



## **Consumer Advisory Council**

### Meeting Minutes

3/4/2013

Members present:

Morry LaTour	Adam Jones	Shannon Caldwell	Jason Jones
Lee Gordon	Jessica Wolfe	Paula Caldwell	Malkanthie McCormick
Elaine Brown	Karen Boudreaux	Harold Kleinert	Jennifer Crawford
Claudia Johnson	Megan Baker	Ashley Candelaria	Norb Ryan
Jeff Edwards	Chastity Ross	Hazel Forsythe	

*Guest and Staff: Lois Smith, Beth Harrison, Bev Harp, David Flechler, Marybeth Vallance, Jana ? (friend of Megan)*

#### ***Welcome and Introduction***

Morry opened the meeting by welcoming all members present at the Coldstream Training Room and those who were attending by live, videoconferencing, Elaine Brown, Jennifer Crawford, Lee Gordon, and Paula Caldwell. At Morry's request, members introduced themselves and related their role as a self-advocate, parent of a child or adolescent with a disability or agency representative.

#### ***Review and Approval of November 19, 2012 Minutes***

Morry asked for members to review the Minutes from the November meeting. He asked if there were corrections or discussion. Chastity made the motion to accept the Minutes with no changes and Malkanthie seconded the motion. Members approved the Minutes unanimously. Both Morry and Shannon expressed their appreciation to Harold for sending the Power Point out ahead of time so they could review prior to the meeting.

#### ***AUCD Update – Council on Community Advocacy (COCA)***

Shannon reported that Harold and he attended the AUCD's Board of Directors meeting in San Diego. He related that the AUCD and COCA leadership were trying to improve the organization's cultural and linguistic competency. In keeping with this goal, members at the meeting recounted their own personal and historical backgrounds, highlighting what each brought to the national Board in terms of cultural and linguistic diversity. The next

AUCD Board meeting will focus on creating greater awareness and competency in cultural and linguistic diversity for AUCD itself.

COCA continues to work on the personal para-transit ID card which will entitle self-advocates and consumers to travel and use para-transit systems while traveling in other areas without going through a new, pre-approval processes. Shannon reminded members to encourage others or share their own para-transit stories on the COCA web-site link.

Additionally, COCA is still advocating for the International Treaty on the Rights of Persons with Disabilities. He remarked that this legislation lost by only 5 votes in the Senate, so it will be re-introduced. COCA is also contacting and encouraging all states' UCEDD's to submit COCA representatives to the Annual Meeting, with the goal that eventually each UCEDD will have a COCA representative. Shannon is proud that other COCA colleagues want to come to KY to see how HDI under Dr. Kleinert includes the voices of self-advocates with disabilities in creating HDI projects and priorities. Shannon noted ways HDI and collaborating state agencies have impacted the lives and career paths of so many self-advocates.

#### ***Core Grant Application Status and NEW Five Year Work Plan***

Harold reviewed the 2013 – 2018 final 5 Year HDI Work Plan. He noted that HDI had already begun planning or had started to work on the priorities of our new Five Year Plan, which we had discussed in the November CAC meeting, and which Harold had sent out for review after the November meeting. The only addition to that Plan was under Interdisciplinary Training, we had added a new Objective 7: "Provide training in rehabilitation technology to 10 pre-professionals, including allied health and residents in physical and rehabilitation medicine."

Morry asked for member approval of Harold's highlighted additions, as well as the submission of the Grant. Karen made the motion; Chastity seconded it and all members approved the motion without further additions. Harold will send this newly completed 5 Year Plan out to members by email and it will be submitted by March 6<sup>th</sup>.

#### ***DD Network Meeting - Friday, August 16, 2013***

Harold wanted members to place this date of the Annual Joint Council Meeting on their calendars. He reported that the joint meeting with the Consumer Councils of the DD Council, P & A and HDI will start at 9 AM and will be held at the Capital Plaza Hotel in Frankfort. Members who need overnight lodging will have arrangements made by HDI staff. Harold noted that CAC members will meet after lunch until 2:30. Karen and Paula will meet with DD and P & A's Consumer Joint Meeting Planning Committee to organize a program theme and activity for the Joint Meeting. Karen encouraged members to email or call her as their Committee met this Friday, March 8<sup>th</sup>.

#### ***Reviewing HDI Progress towards Core Objectives and Year V Revised Objectives***

Members had been emailed a copy of this Progress Report prior to the meeting. Harold was given a correction to make to the date of the emailed report changing Year "4" to Year "5" and the end date to June 30, "2013." He apologized for these date errors. He

reviewed Goal 1), and discussed HDI's Panel with 110 Medical Students and our encouragement to match some of these first year medical students with Mentor Families. He also noted we were on over our 10 student-target for Graduate Certificate students and at target with 10 current Research Assistants.

Under Goal 2), Harold highlighted the TAALC Project, as part of the new KY State Personnel Development Grant, to teach schools to provide a mode of communication for all students. He noted that sadly, still close to 10 percent of students with significant cognitive disabilities were leaving high school without appropriate communication competence or technology. He also discussed that the Community Work-Based Transition Program may become part of KY Department of Education's overall College and Career Readiness model. He noted that HDI was also providing direct training and technical assistance regarding communication competence and access to the general curriculum for students with significant cognitive disabilities to 19 states as part of the National Center and States Collaborative. In respect to our transportation ADA and disability awareness objective, he did discuss that approximately 200 public transit drivers had completed HDI's ADA and disability awareness training but that we needed to expand to transit drivers beyond just central KY as part of the next Five Years' Grant objectives.

Under Goal 3), Harold discussed our work with "Health Matters" teams to improve health and wellness for adults with intellectual and developmental disabilities, and that our KY Supported Employment Leadership Project had developed a "Leadership Series." HDI's Supported Employment staff were serving on KY's Employment First Work Group. In reference to our SHEP project, "THINK COLLEGE" staff from Boston recently came to Northern KY University to film a video of NKU's program, highlighting "Universal Design for Learning" for faculty and as a model for what other post-secondary education programs should resemble. Malkanthie asked a question concerning objective 6) and if the Michelle P. Waiver program had a waiting list. Chastity and Claudia affirmed that there was a waiting list for the SCL waiver but that there was no waiting list for Michelle P.

Harold added that under Goal 3), Objective 5, the KY Office of Vocational Rehabilitation is working on a transition program to enable students with intellectual disabilities to attend college, and that Carl Rollins introduced a bill that has passed the KY House that would provide KEES (KY Excellence in Education Scholarship Funds) for students with moderate and severe disabilities to attend college.

Lastly, under Goal 3), Harold reminded CAC members that though the Migrant Grant has ended, OVR was still doing some activities in this area. He also explained that under Objective 9, we would not duplicate the DD Council's goal of creating a Parent Mentor program but that we were working with Life Plan of KY to establish a Pooled Special Needs Trusts for KY. Members noted Carolyn Wheeler's expertise in this area, but many members noted that there was a "disconnect" between Social Security not knowing or correctly advising individuals. Members strongly noted that this "barrier" was often harmful to persons who are receiving Medicaid.

Under Goal 4) (Research), Objective 3, Supported employment agencies are now entering data into a state-level Supported Employment database. Under Objective 4, HDI's Early Childhood KEDS data system now tracks performance of all of KY's preschool children, and is analyzing the extent to which children with developmental delays are closing the gap in learning outcomes in comparison to children without disabilities or delays. Under Objective 6, Harold commented that Dr. Missy Jones of NKU and a former SHEP Research Assistant (Zach Goble) had published an article on the outcomes of peer mentoring for college students with intellectual disabilities. Dr. Jones and Dr. Kathy Sheppard-Jones had collaborated on a Research Brief in press, for "Think College" on the importance of concurrent work and post-secondary educational opportunities.

Goal 5) Dissemination was highlighted by Harold's distribution, during the meeting, of HDI's 2013 Winter Newsletter and Winter Research Brief. He remarked that the Research Brief was also sent out to each school district in KY. Malkanthie asked Harold to explain the outcome tables in the Research Brief and Harold noted that the most significant impact on employment after school was a *paid job during school*. Harold also answered her query by explaining that the post-secondary data were based on 2011 graduates, so the data collected and analyzed during the summer of 2012 (one year after these former students had left school) are the most current data. Also, he explained the in Table 2, adolescents with intellectual disabilities fared worse in both going onto higher education and competitive employment. He also noted that the Research Brief had "Research to Practice" tips discerned from the data. Lee asked a question about data concerning adolescents with autism positively correlating with higher education but negatively correlating to obtaining employment. Harold confirmed Lee's comment on the data in the Research Brief. Paula commented that with the new Joint Councils' focus on helping self-advocates share their stories and gain greater self-expression, that this, also, may be a positive contribution toward employment success. Marybeth added that HDI's statewide April 19<sup>th</sup> Seminar was focused on adolescents on the Autism Spectrum and their transition into adulthood, further higher education or employment.

Harold reviewed with members the remaining progress on objectives in Goal 5 and noted that this review was a mandatory part of the DD Act.

***Project Spotlight – HDI's Supported Higher Education Program (SHEP)  
See Power Point Presentation\****

Bev Harp reviewed the history and process of the SHEP program, highlighting case studies with actual student successes. Goals of SHEP focus on creating a statewide model of Supported Higher Education with a goal of providing outcomes-based postsecondary opportunities for students with intellectual disabilities. Person-centered planning is the basis of assisting students in thinking about and achieving their education, vocation and social goals. Each student in SHEP has an education support team, consisting of SHEP staff and practicum students, family and other supports, tutoring or peer-mentoring as determined by the student. Sixty-five students have been supported through SHEP to-date. Eight students are involved in a pilot project with KY OVR.

Ten students have completed semester-long internships and six students are currently working in paid positions. Comprehensive Transition and Postsecondary programs are in process with NKU, Murray, Kosair's Spalding and ECU. Bev suggested that as she could not show the video to all remote CAC members attending today, those interested could view the SHEP video on the website, [www.shepky.org](http://www.shepky.org).

CAC members asked Bev for clarification if adolescents with IEP's who did not have high school diplomas, the ability to pass the college-entrance exam or a GED were, at present, only able to audit courses at the participating community colleges and universities. Bev noted that a number of the SHEP students wanted to continue to take courses for credit, but that the absence of a diploma, college-entrance exam passing grade or GED, was an obstacle to students getting credit or achieving a degree from the higher education institution.

Hazel asked if SHEP was measuring outcomes and Beth Harrison noted that "THINK COLLEGE" was their national data collection site. Beth confirmed that positive outcomes will be crucial to obtaining further funding for SHEP programs. Beth noted that they are also exploring individual goal achievement data collection. Karen noted that the emphasis on children with intellectual disabilities achieving diplomas started with teacher attitudes even in elementary schools. Bev agreed and remarked that the new KY Alternate Diploma and College Career Readiness national education projects may positively influence more students with intellectual disabilities obtaining high school diplomas.

#### ***New Member Status for CAC***

Harold apologized that with the time required to prepare the new 5 year grant, he had not contacted Kathy Jo Edwards. He promised to ask her about her willingness to join the CAC and also asked members to contact him if they knew any interested self-advocates from northern KY willing to join the Council.

#### ***Agency Updates***

##### ***Protection and Advocacy***

Jeff distributed to members the P & A "Rights Reporter" and will also send e-copies of this publication to CAC members. He reported that P & A will sponsor in mid-May, a community "clean-up" of the old Frankfort State Hospital and School Cemetery. He also noted that there was a special committee focused on raising funds for a Memorial Marker, commemorating those who died and were buried "unnamed" after their inhumane residence at the now defunct institution.

##### ***DD Council***

Adam Jones reported that the DD Council was getting ready to submit their Annual Report to the Federal Government funding authority. He stated that the DD Council had 24 on-going projects, focusing on employment, education and health. Regarding their employment goal, the DD Council was trying to get employers involved. To promote their goals for improved and inclusive education in KY, the DD Council had contacted

Eric Carter at Vanderbilt who had researched and published articles about best practices in education. In their health initiative, they plan to focus on more training, also modeling after HDI's training modules, for health care providers who are not physicians.

***Department for Behavioral Health and Developmental and Intellectual Disabilities-***

Claudia reported that the Department was focused on the implementation of the newly-revised SCL waiver components. The new regulations were effective February 1<sup>st</sup>. June is the projected time to begin transitioning individuals' person-centered plans to the new services. Claudia stressed that the Department was still holding training sessions for case managers and also holding self-advocacy meetings to answer questions as many people still had questions about the impact of the changes which stress person-centered plans and enhance supported employment rates. Marybeth asked Claudia or Harold to circulate any Department public meetings for self-advocates and their parents or guardians in the event CAC members still wished to attend.

***Commission for Children with Special Health Care Needs***

Lee reported that the Commission continues to have the "Family to Family (F2F)" grant for 1 more year. He explained that this program had 2 parent co-directors and support parents at their Commission sites around the state. Also, he highlighted the Commission's continuation of the Early Hearing Detection grant for newborn nursery hearing tests. He reminded members that Terri Williams was continuing to work across the state to promote education and the practice of adolescents' active participation in their education and health care planning from Pediatrician care to Adult Health Care Providers. The Commission, he reported, is starting on its next 3 year goal and project planning.

***Office of Vocational Rehabilitation***

Jason reported that their Office was looking at several New England states' implementation of "Employment First," which promoted adults with disabilities having employment as their first outcome, including the possibility of jobs in state agencies. OVR is also organizing a Team to look at promoting success in employment for those on the Autism Spectrum. Regarding quality casework and moving rehabilitation case-actions more quickly, Jason reported that their new Executive Director was reviewing methods on assessing quality casework not simply on successful closure of cases but on "weighting" the challenges faced by the individual in achieving a job (giving more weight when significant challenges were overcome). Jason explained that the newly discussed goal would be a clear method to reward OVR counselors for weighed-positive outcomes for their cases, whether the length of the case was years or a shorter period.

***State ADA Office***

Norb Ryan announced that he met with the Governor 3 weeks ago to give his last year's report. He summarized that last year, 500 people contacted the ADA Office and 120 contacts turned into actual cases. His office also conducted a Seminar last year for ADA Coordinators at Universities and had 93 people in attendance. The ADA had surveyed all KY Polling Sites for accessibility and Norb added that he had to go to 5 or 6 counties to insure that they completed their Accessibility Report for voting rights. He concluded

that all KY Polling Sites are accessible. This spring, Norb and his Assistant will look at accessibility of state parks, as well as domestic violence and rape crisis centers. Jason reminded Norb that a survey had been completed on state parks' accessibility and Norb was going to meet with the coordinator of that project. Norb also explained that any swimming pool open to the public (including Ys, hotels, etc.) had to provide an appropriate lift which met standards and enabled persons with disabilities to get in and out of the water.

#### ***New Business and Announcements***

Karen reported that March was Down Syndrome Recognition Month and March 21<sup>st</sup> was the actual day of recognition and celebration.

Marybeth explained the topics of HDI's April 12<sup>th</sup> Seminar, "*Navigating the Challenges of Transition: Supporting Youth in Educational, Community Living and Pediatric-to-Adult Health Care Planning*," by the Commission for Children with Special Health Care Needs staff and April 19<sup>th</sup>, "*Transition and Beyond for Youth and Young Adults with Autism Spectrum Disorder*," by Drs. Lisa Ruble and Jon Campbell in the Department of Psychology at U.K. Seminar Flyers were distributed to members with Marybeth highlighting that members could register for one of the 18 live, video-conference Seminar sites through the hyperlink in the flyer or through the HDI home web-page.

#### ***Lunch and Meeting Conclusion***

Morry reminded members to turn in their Reimbursement Forms. Harold reminded members that all members will be asked to attend the next meeting at the Coldstream Training Room on Monday June 3rd for better face-to-face networking and discussion. He then emphasized that members place August 16<sup>th</sup> on their calendars for the Joint DD Network Meeting and HDI CAC meeting at the Capital Plaza Inn, Frankfort.

Harold also gave a special "thank you" to David Flechler for helping with the video-conferencing connections of remote members and for his expertise with problems some members experienced with their connectivity. Members voted unanimously to adjourn and members could network further over the provided lunch.