



Consumer Advisory Council

Meeting Minutes

4/2/2012

Members present:

Morry LaTour	Jessie Birdwhistell	Shannon Caldwell	Paula Caldwell
Lee Gordon	Claudia Johnson	Hazel Forsythe	Malkanthie McCormick
Jason Jones	Peter Perry	Harold Kleinert	
Sandra Duverge	Megan Baker		

Guests and Staff: Marybeth Vallance, Ruth Caldwell, Terri Williams

Welcome and Introduction of Board Members

Morry LaTour welcomed the members in attendance and called the meeting to order. Members were asked to introduce themselves. Harold noted that Chastity apologized for having a family issue and needing to miss the meeting and he thanked Morry for chairing the meeting today. He also reported that Karen Boudreaux had been helping an ill father and had recent surgery herself. Pam Mattox had called to report that she was unable to attend due to family illness. Harold announced that he had invited Terri Williams, a Program Administrator of a new grant-funded program aimed at health care transition issues of youth with special health care needs. She would be sharing information about her program as part of the meeting's agenda.

Review and Approval of December Minutes

The minutes from the December meeting were reviewed, voted on and approved with Peter making the motion to approve the minutes and Malkanthie seconding the motion.

AUCD Update – Council on Consumer Affairs

Shannon Caldwell, CAC-COCA liaison, gave his report as COCA representative to the AUCD Board. He reported that Board members had just met in Phoenix, Arizona. The Board hopes to create new ideas and initiatives in the areas of transition through building on programs currently existing.

In the COCA Steering Committee meeting, Shannon reported that they discussed the "Universal I.D." concept in greater detail. COCA has set up a Blog asking members for comments and stories about para-transit. Shannon addressed previous questions that the CAC members had about the Universal I.D. concept by explaining that consumers find it

difficult to travel to different counties or states, as eligibility for para-transit varies county by county and state by state. As para-transit companies require prior-approval for anyone to use their system, this requires consumers faxing duplicate or new documentation prior to being approved to use para-transit in different areas of travel, and this can also result in lengthy wait times. The goal of this “Universal I.D.” concept was to potentially standardize all para-transit eligibility guidelines. Harold noted that the Joint Councils Transportation Target group found the same discrepancies among para-transit in counties throughout KY. Morry affirmed this problem in making plans to attend a meeting out of state. He shared his difficulty in having to meet the eligibility criteria of an out-of-state para-transit company and this involved filling out papers, providing documentation and faxing all his materials, as well as the uncertainty if the company would approve his temporary para-transit request. Shannon requested that members go to the COCA blog to post their stories or thoughts on this idea. Harold sent out the link to everyone.

Shannon also reported that COCA was going forward with the goal of U.S. Congressional ratification of legislation supporting the advocacy for legal rights of persons with disability across the world. Also, Shannon had attended a State Center for Accessible Living Council meeting which highlighted the problem of no uniformity of accessible parking regulations across KY. Morry reported that the Lexington-Fayette Commission for Citizens with Disabilities had been focused on this same issue and that a film clip developed by the County Clerk’s office was to be shown during the April 26 “Celebrate Disability Expo” showcasing many examples of violation of accessible parking spots. Jason Jones agreed with this problem and noted that even people with disabilities having a car would often park in a spot reserved for a van driver. Spacing for van parking was not standardized throughout the state and Jason emphasized that no educational material was given by the state for people applying for an accessible placard. Lee Jordan added that the state also had no statutory standards guiding physicians in completing the applications for an accessible placard.

DD Network Joint Transportation Target

Paula presented the summary on this Joint Council initiative, which involved collaborative meetings at the DD Council with representatives of all 3 Advisory Councils. She summarized the existing problems which prompted this target project; one being that many companies offered free transportation in rural counties *only* for medical transportation. Also, she stated that a few KY counties did not have transportation systems. She summarized by stating that the Committee decided that the problem was too large for it to tackle statewide uniformity and accessibility of transportation. The Committee concluded that producing a KY Transportation Resource Report would give individuals and communities the resources available. Harold sent this “Transportation Report with Maps” electronically to members during the meeting. Shannon also noted that the report showed wide discrepancies regarding the costs charged by different transportation services. Harold noted in a conclusion statement that all projects started or supported by H.D.I., the DD Council and P&A should consider transportation access.

HDI Transportation Provider Training Update –

Marybeth reported that HDI continues participation by consumers in face-to-face training with Lextran when they have a new drivers' class of more than 7 drivers. She noted that Lextran fully supports the ADA Drivers' Training Module and that all new drivers take this module during their orientation and training period. She also reported that HDI had submitted will do a 3 month follow-up survey on all the 118 drivers who initially took the training module. The purpose of this follow-up is to assess the impact the training made on drivers' attitudes and interaction with riders having disabilities.

Morry reported that he is on Wheels Para-transit Consumer Advisory Committee and that there was discussion that all Wheels drivers may also have to take the training module. Marybeth and Harold noted that edits and some new scenarios may be needed to adapt the module for para-transit drivers. Harold emphasized that it was the hope that other transportation systems in the state might utilize the Training Module.

Lee reported that TARC in Louisville had a Consumer Advisory Committee for many years. Marybeth stressed that members in our CAC consider advocating for Consumer Advisory Committees within their existing transit companies and remarked that changes may occur through this kind of advocacy, as proven by Louisville and Lexington.

Reviewing HDI Progress toward Core Objectives and Year V Revised Objectives, DD Network Needs Assessment

Harold reported that AUCD requires that UCEDDs give a report on the Core Objectives to their Consumer Advisory Councils. He noted that our problems in meeting our Core Objectives were notable under ***Goal 1*** and that he would discuss the changes we had proposed to national under ***Goal 1- objectives 1 and 2***. Each CAC member had the report and Harold highlighted some of the significant areas.

He noted that under ***Goals 1 and 2***, we had already exceeded our projected number of courses taught, with 20 courses taught this academic year by HDI staff and faculty. We have 11 Certificate students completing their leadership projects this academic year and HDI was meeting the training module participation for dentists and physicians taking the "Perservice Health Training" modules. He noted that HDI was proud of the opportunity to award 8 grants to recreation providers to support accessible and inclusive recreation.

Under ***Goal 3***, he reported that our Quality Enhancement team in early childhood education provided assistance for 833 early care and education programs, well over the projected goal of 50. We are implementing the "Health and Wellness" Initiatives across the state to providers. Under ***objective 5)*** we are working with 6 colleges re the Supported Higher Education Program. Under ***objective 6)*** Waiver programs in KY are now providing more emphasis on supported employment and Milt Tyree is expanding his training to supported employment providers. Under ***objective 10)***, Harold noted concern regarding the future of the Migrant Workers' Grant, as it is in its last year of funding.

Under ***Goal 4, objective 4)***, Harold reported that under the KEDS initiative, we had assessed school-readiness for almost 40,000 children in early intervention/early childhood.

Sandra Duverge asked who conducted Kentucky's parent engagement survey for students with IEPs, and Harold explained that the KY Department of Education does random surveys in large school districts and sometimes surveys all parents with children having IEPs in smaller school districts. Tony LoBianco further explained the method of parent survey collection. He reported that Fayette and Jefferson Counties surveyed every year and other districts did parent surveys every 6 years.

Malkanthis asked when the results of the *KY Post School Outcomes Survey* for former students with IEPs would be available, as well as the results of the annual Parent Engagement Survey. She asked that these be presented to our CAC. We agreed that these could be presented at our December or March meeting.

Under **Goal 4, objective 1**), Harold highlighted all HDI publications and manuscripts. For example, 4,000 copies of Life after High School highlighting successful stories of young adults transitioning into jobs and higher education had been distributed, in addition to those "pdf" copies downloaded from HDI's web.

Harold ended the CORE Workscape Objective Report by discussing the amendments made to **Goal 1, objectives 1) and 2)**. He noted that HDI's discontinued role with the Behavior and Developmental Pediatric Residency Program was not within HDI's control. He noted that he and Marybeth had an upcoming April meeting with the Director of the Pediatric Residency Program to discuss future collaborations or Mentor Family matches that might be possible within the Residency curriculum. Marybeth will also be working with faculty and preceptors for medical school students to discuss student-Mentor Family matches and possible Mentor Family Panels during the 2013 academic year. Lee offered to facilitate connections to the Family to Family Consultants with the Commission of Children with Special Health Care Needs if more mentor families are needed. Also, Sandra stated that she had personal connections to a faculty member at the Louisville Seminary, if we wished to collaborate with them in infusing mentor family matches into their curriculum. She also said that FIND of Louisville had families in that area who might agree to be Family Mentors and she could help recruit families if needed.

Malkanthis questioned how many Pediatricians or even faculty within the College of Medicine were aware of the "Brighter Tomorrows" training for physicians to give unbiased information to parents when providing a prenatal or post-natal diagnosis of Down syndrome. She hoped that this might be addressed through Harold & Marybeth's collaboration meetings to again infuse HDI elements into the Residents' training.

Harold explained that prospective parents are often *not* given accurate and balanced information about Down syndrome. He reported that research has shown 90% of prospective parents were opting to terminate the pregnancy when prenatal tests showed this diagnosis, but they may have lacked basic information to even make informed decisions. Harold summarized by reporting that HDI had taken a lead role in advocating that accurate and balanced information about Down syndrome be given to parents by physicians after a positive pre-natal diagnosis of Down syndrome.

PROJECT SPOTLIGHT:

Dr. Mike Abell was the invited HDI Project Director to highlight the Mid-South Regional Resource Center mission and scope of activities. Mike shared his background as a school psychologist and local special education director. He reported that Mid-South is directly under the U.S. Office of Special Education. Mid-South serves 9 states, including the District of Columbia. Mid-South, as similar projects under the Office of Special Education, provides technical assistance and monitors progress and compliance for school districts relating to special education.

Mike described a Progress Chart from 1973 through 2008 that detailed school progress in achievement measures, noting that progress during this extended period was flat across all students. He stressed that these data have prompted the U.S. Dept. of Education to look at evidence of programs which *do* show an increase in learning and achievement. Mid-South is currently focusing on how we can move away from compliance monitoring to researching and sharing strategies and programs that *do* show positive gain in learning measurements. One such intervention is the promotion of reading in early intervention programs. A disappointing aspect of some of these positive outcome programs is that many of them are based on time-limited grants, so even though positive gains were achieved, the funding for these interventions ended.

Mike was asked how the new DSM -5 for Autism Spectrum Disorder (ASD) will impact children eligible for special education services under the Autism label. He discussed that there was a dis-connect in that state school psychologists will continue to use the autism spectrum criteria developed under IDEA, yet, some families may seek an evaluation done by an outside specialist who would probably use the revised DSM-5 criteria in the future.

Parent engagement was another positive indicator of school success and Sandra asked if Mike had data which measured the outcome of positive parent engagement with school children. Mike related that he had not researched this indicator, but stressed that parents' who knew and targeted their engagement with can improve their child's outcomes.

Lee commented that progress measurements should not be based on test scores, as they often do not accurately measure learning for children with special needs, but, the measure of success in schools should be based on how many students have graduated. Mike summarize his presentation that Mid-South would continue to explore exemplary programs and work with the Office of Special Education to implement programs which have shown a rise in learning and achievement.

Nominating New Members for CAC

Harold reported that we need 2 parent nominations from Western Ky. Members were given a Bio from one parent nominee from Paducah. A motion was made by Hazel to accept Elaine Brown from Paducah as a new member and Malkanthie seconded the motion. The motion passed unanimously. Malkanthie inquired if members could choose to participate through distance connections and Harold confirmed that HDI had purchased a new camera for this. Lee mentioned that he knew another mother with with

the Commissions' Family to Family Connection and that, if interested, she and Elaine could choose to participate via interactive videoconference through their Paducah office.

Harold showed the chart of HDI CAC member terms and it revealed that 5 members' terms would expire in December, which represents a major change in our CAC membership. He asked that members consider additional self-advocates and families and send bios to Harold and Shannon. Peter, Sandra, Karen, and Shannon comprise the Nominating Committee.

New Criteria for DSM-5 for Autism Spectrum Disorder

Harold discussed the criteria for both the old and proposed revisions. He and others commented that the new definition may not cover all present children with IEPs under this label and may affect Michelle P Waiver eligibility. Harold reported that HDI will work with other groups concerning the enactment of the new DSM-5 ASD revisions.

Agency Updates

Lee Gordon from the ***Commission for Children with Special Health Care Needs*** reported that the Commission was requesting comment on their new Block Grant. He gave the information that members could submit their public comment.

Harold welcomed Terri Williams, Health Program Administrator for the relatively new, ***KY Integrated Services for Children and Youth with Special Health Care Needs***. Terri reported that this new program was funded until June of 2014. The focus is on helping students with disabilities and special health care needs to move through the transition process from pediatrics, to specialists, to adult care providers. The goal is to reduce duplication of services and build a registry of physicians willing to treat young adults with special needs over 18. Terri's program is working with the "Medical Homes" program and looking at the educational information physicians need to accept youth with disabilities. Terri will meet with Marybeth & Harold to discuss work with HDI projects.

Claudia Johnson, ***Department of Behavioral Health, Developmental and Intellectual Disabilities*** noted the state budget has passed and the Division was one of the only state entities without cuts in their budget. SCL Waiver changes are being revised and are focusing on more funding for supported employment and more person-centered planning.

Jason reported for the ***Office of Vocational Rehabilitation***. He noted that OVR's annual state conference was in April. OVR is working toward bring the KY Assistive Technology Network into the OVR structure.

Morry then asked for any interested persons to let him know if they wanted to be on the ***Wheels Para-transit Consumer Advisory Board***.

Next Meeting- The August Joint DD Councils will be the next meeting and Harold will send the announcement of this meeting date and location to members. **We adjourned.**