

Commonwealth Council on Developmental Disabilities - November 2003 Meeting Minutes

Approved February 11, 2004

KENTUCKY COUNCIL ON DEVELOPMENTAL DISABILITIES

FULL COUNCIL

NOVEMBER 13, 2003

MINUTES

WORK SESSION

Pat Seybold introduced Dr. Ed Jennings, University of Kentucky Martin School of Public Policy. Dr. Jennings presented an overview of the different things that the Martin School has been working on with the Council. Following are the projects that the Martin School has been working on: 1) Capwiz; 2) Position Statements; 3) Agenda for the 2003 General Assembly; 4) Transportation Work Group, Hope for Better Transportation, also attended the National Summit on Transportation for People with Disabilities in Rural Settings; 5) Improper use of handicap parking spaces; 6) Medicaid card distribution policy; and 7) Developed and initiated a process for reviewing proposed legislation submitted for the 2004 session.

FORMAL MEETING

MEMBERS PRESENT: Bethaney Adams, Diana Berry, Marie Braun, Dave Matheis, Diana Chism, Jeff Edwards, Debbie Gilbert, Stephanie Gullely, Elbirda Haley, Harold Kleinert, Chris Kramer, Claudia Johnson, Beth Cross, Wanda Propes, Chastity Ross, Michelle Skillman, Holly Smith, Donna Collins, and Linda Williams

MEMBERS ABSENT: Melanie Cole, Cathy Jo Edwards, Paula Giddens, David Hanna, Gayle Rees, Paula Jackson, and Preston Lewis

STAFF: Pat Seybold, Vicki Goins, Adam Jones, Patty Martorano, and Wilma Cox

GUESTS: Roberta Emmitt, Attendant; Jan Richards, Department of Education; and Cheryl Davis, Department for Medicaid Services

Call to Order: Diana Berry, Chair, called the meeting to order at 10:00 a.m.

Conflict of Interest: None noted

Introductions: Everyone introduced himself or herself.

Proxy Announcements: Wanda Propes will be proxy for Holly Smith at 1:00 p.m.

Additions to Agenda: Marie Braun has information for the Quality Assurance Work Team. Debbie Gilbert announced that the Education Work Team will meet today at 12:30 p.m.

Approval of May 22, 2003, Minutes: ROSS/BRAUN Motion to approve August 21, 2003, minutes with corrections. MOTION PASSED.

Chair Report - Diana Berry

DISCUSSION - September 11-12, 2003, an Individualized budget training budget of 1 individual with a disability. On October 3, 2003, attended the Advocates in Action program gave welcome, handed out KCDD information folders

On October 17-19, 2003, attended Women with disabilities and Allies Forum in Bethesda, Maryland. Gave ideas to use for 2004 NACDD Fall Conference in Lexington. On November 9-11, 2003 attended the NACDD conference in Salt Lake City, Utah. Also attended the Business meeting November 9, 2003, adapted strategic plan, approved finance team as standing team, approved NACDD as partner in Alliance for full participation, gave handouts. Attended the following sessions: Aging and intellectual and DD; Real Choices Real Life; Round table for Chairs; Public Policy team meeting; Training Law Enforcement; and Youth and Leadership. Formed a conference planning committee for NACDD 2004 to be held in fall in Lexington Committee. Persons who volunteered are Chastity Ross, Wanda Propes, Diana Berry, Bethaney Adams, and all the staff. Also asked for Council member to volunteer for PNS Family Support Grant- Debbie Gilbert, volunteered. Asked for volunteer to help plan a 'Work Support Rally ' Marie Braun volunteered and Maria also volunteered for Olmstead Committee.

QA - PNP- KY self-advocates for freedom filed their articles of incorporation, they spoke at HB 144 Commission meeting, opened a bank account, spoke at P&A Advisory Board.

Consumer Involvement Fund - sponsored 13 individuals to attend the National Down Syndrome Conference, Deaf/ Blind Conference, International Charge Conference, Autism Conference and Reinventing Quality Conference.

Formal and Informal Community Supports - Advocates in Action focused on recruiting, 68 applications received, 30 participants chosen. 10 alternatives chosen, Wilma Cox and Wanda Propes attending this year.

Council on Mental Retardation - Established local self-advocacy Chapter 'Advocacy Connection of Metro Louisville'. Seven consumers obtained roles on decision-making boards, 2 participants have found jobs, 1 found an apartment, and a mother found better services for her son

Executive Director - Pat Seybold

MTARS - Staff held a mock MTARS in preparation for federal visit next year or so. All items were satisfactory except one item was referred to the feds.

NACDD Hold Harmless - Has been passed waiting for President's signature.

NACDD Conference - Strategic Plan approved. Three new committees approved. Bylaws, finance and strategic planning members encouraged to sign up. Alliance for Full Participate Conference in 2005. TA contract for Councils/conference in June and Planning Conference. Public Policy seminar in March.

Grant Announcement - PNS Family Support Grant approved. Commission for Children with Special Health Care needs will have an advisory board. They are seeking a Council person. Debbie Gilbert volunteered.

UEC - Director nominated for award.

HB 144 - To meet in December to review recommendation for HB 501 committees. Noted Ed subcommittee working on employee education/informant.

DSA Review - A part of MTARS review process no significant issues found.

Website - Continue to have problems will continue to seek removal of barriers with Cabinet

Propes Article - Wanda Propes has an article in the Frankfort paper.

2004 NACDD conference will be held in Kentucky. Names of interested council members and other NACDD member who would like to be on the committee.

Membership Committee - Paula Jackson/Absent

Chastity Ross reported that the Membership Committee is working on an Orientation Manual. The committee will be meeting following the Full Council meeting.

Council Affairs - Marie Braun

DISCUSSION - Member Reimbursement Policy was discussed. HALEY/GIBLERT Motion to accept the Member Reimbursement Policy as written in the meeting book. MOTION PASSED. Also discussed the Process for Completion of Executive Director's Evaluation. ROSS/KLIENERT Motion to accept adding #8 on the Process for Completion of Executive Director's Evaluation. MOTION PASSED. Discussed developing a policy so the Executive Director can receive an increment. ROSS/CHISM Motion for Council Affairs committee to develop a new policy tied to the evaluation, for the Executive Director to receive increment. MOTION PASSED. ABSTAINED/KLEINERT. ROSS/PROPES Motion to accept the Council Affairs report. MOTION PASSED.

Public Policy - Elbirda Haley

DISCUSSION - There will be a Public Policy meeting on November 14, 2003. Dr. Ed Jennings provided an update in his presentation this morning. On January 14, 2004, from 11:00 - 2:00 p.m., the United 874K Coalition will have a Rally in the Capitol Rotunda. The Council will fund \$1,000 for this event. The Council will have a breakfast for the legislators on January 22, 2004, in the Annex Cafeteria. MATHEIS/BRAUN Motion to accept this report. MOTION PASSED.

Formal and Informal Community Supports/Quality Assurance - Diana Berry

DISCUSSION - The Advocates in Action's first training was held October 3-5, 2003, at the Holiday Inn in Frankfort. The next training will be January 13 - 14, 2004, at the Holiday Inn in Frankfort. Wanda Propes and Wilma Cox will be attending this training.

Education - Debbie Gilbert

DISCUSSION - Access to Better Choices - An Inclusion Project is in its 3rd and final year-it's goal is to have 40 students attain 80% inclusion. To date, 28 of the original customers have attained 80% inclusion and 15 customers have increased their time by 50%. Twenty-two customers want to remain with the project for follow-up and to try and reach the 80% inclusion goal. Due to the decrease in the number of customers, one Inclusion Coordinator has been hired and the use of a parent/mentorship model is being used for follow-up. They have been busy attending ARC meetings, meeting with the customers and distributing "No Child Left Behind" materials with both customers and school personnel. Efforts are underway to secure funding for the continuance of this project after DD funds end this year.

The Governor's ADA Task Force on Postsecondary Education Project has been making presentations at various conferences and collaborating with schools/institutions, agencies, etc. that are involved in postsecondary education. They are currently working with Kentucky Virtual University to provide web

page accessibility and with the Administrators at institutions to develop a lending closet for adaptive equipment that all institutions could utilize. Also, meetings with the Council on Postsecondary Education are being planned to establish guidelines and a repository for accessible textbooks. The project staff reports the members of the Task Force have developed a very close and productive relationship and are now using each other as a support system.

The Inclusive Education Initiative Project have twenty-four students included 75-80% of their day in the five model schools. The model schools have collaborative teaching models in place and the schools are continuing their self-assessment with their critical friend for improving the quantity and quality of the inclusive ed. opportunities for the identified students. Schools are utilizing their mini-grants to fund specialized training opportunities as in collaborative teaching, autism training, and assistive technology. The next 5 schools were selected and all ten schools attended a "kick-off" meeting in September. Six of the ten principals participated in a focus group about school council issues related to students with disabilities. Also, Clark Middle School was chosen by a national publication Education Week as a school committed to improving results for all students including those with disabilities. Dropout rates and student assessment results from the schools are currently being analyzed. Preliminary analysis indicates that Model Middle and Greenwood H.S. still rank in the top ten schools of their level across the state. The project is on target to meet its target.

The Education Target Team has been meeting to develop strategies to meet the State Plan Target-By 2006, 40 children with developmental disabilities will be appropriately served in integrated early childhood or day care programs.

Health - Elbirda Haley and Harold Kleinert

DISCUSSION - The Preservice Health Training Project held a planning meeting on Oct 10 to begin the development of the Nursing/Physician Assistant Module's. The core team for these modules consists of the following: core faculty, technical advisors, two individuals with disabilities, two parents of children with disabilities, and a nurse practitioner student who is also the parent of a child with a disability. Work with KYVU to insure that the modules will be compatible with KYVU's software continues and completely accessible for users. The major challenges being encountered is insuring adequate time for script development for all key team members, given their other responsibilities and the many technical issues that arise as development proceeds. The project staff reports they are on target to meet overall milestones of involving the three state's medical schools in adopting these modules into their coursework during the 2003-04 academic year.

Employment - Dave Matheis

DISCUSSION - Project ASSET 2002 continues to make progress towards reaching its goals. Ten support teams are active and in various stages of business planning and operation. Each team has a Supported Employment Service Provider represented on the Team, active with planning and development on behalf of the business owner. The major problem-the time it takes to develop a plan and put into place all the various components necessary-continues to slow down the projects ability to meet it's originally proposed targets. Even with delays, the project staff reports that all fifteen businesses will have gotten started.

QUALITY ASSURANCE - Diana Berry

PNP - Kentucky Self-Advocates for Freedom filed Articles of Incorporation with the Secretary of State. They spoke to the HB 144 Commission. They also opened a bank account.

Consumer Involvement Fund - This quarter the CIF was used to sponsor 13 individuals to attend conferences/training are related to various disabilities including National Down Syndrome Conference, Deaf/Blind Conference, International CHARGE Conference, Autism Conference, and the Reinventing Quality Conference.

State Agencies

DISCUSSION -

1. **MH/MR** - Claudia Johnson

MH/MR: Refer to the HB 144 summary in the meeting booklet for information on current activities.

SCL allocated another 150 slots in September and have 200 allocations scheduled for December '03.

Margaret Pennington is retiring at the end of this month, reception at Central Office scheduled for November 25, 2003 from 2:00-4:00 p.m., in Large A&B conference room.

Secretary Morgan is also leaving this month and her reception is scheduled for November 20, 2003 at CHR, 2nd floor Board Room, from 2:00-4:00 p.m.

2. **Dept. of Education** - Jan Richards reported for Preston Lewis.

Federal monitoring to occur next week. No public comments as monitoring was satisfied with previous visit.

3. **Medicaid** - David Hanna - no report

4. **Dept. for the Blind** - Beth Cross

The Department for the Blind fiscal year ended September 30, 2003. This date brought to an end a very productive year for the agency. The Department served 2,718 consumers and of these, 355 individuals achieved their vocational goal. This was a 15% increase over those going to work for fiscal year 2002. The total gain in earnings by consumer's serve was \$1,557,411.44. The Independent Living Program served 998 consumers, providing much needed service to help maintain individuals in their homes rather than nursing homes. The Charles McDowell Rehabilitation Center in Louisville received a donation of 5 acres of land from the Kentucky Department of Juvenile Justice. This land will be developed for future programmatic and recreational expansions. The Department's two recording units in Lexington and Paducah have been upgraded to provide digital recording and Braille services across the Commonwealth.

5. **Dept. for Public Health** - Diana Chism

FOLIC ACID

- o 83,714 women received folic acid supplementation from July 1, 2002, through June 30, 2003. Additional 2,022 women of childbearing age received counseling on folic acid.

- o The percentage of women 18 – 44 reporting knowledge of folic acid aiding in the prevention of birth defects went from 32.3% in 1997 to 48.1% in 2001.

- o The percentage of women 18 – 44 reporting taking a multivitamin or supplement containing folic acid on a daily basis went from 29.9% in 1997 to 39.6% in 2001.

- o In 1996, there were 67 babies born with neural tube defects in Kentucky compared to 26 in 2001. This represents a 60% decline in these serious birth defects of the brain and spine.

HANDS

- o Voluntary home visitation program for first time parents to promote healthy growth and development of the child.

- o 120 counties served.

- o 8,789 families receiving services.

- o 343 eligible families declined home visitation.

- o 777 families elected to exit the program.

- o 5,248 assessments completed.

- o 35,670 professional visits were completed.

- o 69,622 paraprofessional home visits were completed.

- o Total services were 110,540.

6. **Dept. for Aging** - Donna Collins

Regional Olmstead Informational sessions are being held. We just completed the 5th meeting in Somerset. There will be one more meeting on November 25 at Madisonville Community College. We have included and invited the Kentucky Hospital Association, Kentucky Home Health Association, Kentucky Housing Corporation, and Kentucky Assisted Living facilities association. In sharing resources and collaboration, we feel that our outcomes are being met. The Olmstead brochure "Community Choices and Services" is complete and copies are being distributed.

OAS applied for an Aging Resource Grant that was denied. We will reapply. This grant was to establish infrastructure for single point of access to resources in the community.

The Bluegrass Healthy Aging Coalition presented the "Successful Aging for Individuals with Disabilities and Their Caregivers" on October 30. There was great attendance and very informative. Particularly the long-range planning information.

Office of Aging held a case managers training in October, that was very successful.

7. **DVR** - Dave Matheis

The Department assisted 4,773 Kentuckians with disabilities to achieve positive employment outcomes during the federal fiscal year that ended on September 30, 2003. This represents about a 5% increase from the previous fiscal year and is the highest number of outcomes produced by the Department since 2000. The Department achieved this increase despite budget limitations necessitated by the state's budget crisis. Staff travel has been severely limited and there have been restrictions on filling open positions. Although the Department's office personnel cap is 504 individuals, we currently have only 465 employees and are not likely to expand that in the foreseeable future.

The Department will be focused on transitioning to a new administration.

The early results of Project ASSET, our collaboration with the DD Council have been encouraging. We will be expanding it in the coming year at our own expense to serve five individuals with mental health diagnoses.

The Kentucky Assistive Technology Loan Corporation has been lending money for assistive technology for three years. We have made about 100 loans for over \$600,000, with about half of those loans coming in the last six months after we were discovered by hearing aid vendors. The bulk of the loans have been for hearing aids or modified vehicles. KATLC recently received another grant from the National Institute on Disability and Rehabilitation Research (NIDRR) for \$142,000. We now have \$1.8 million available at Fifth Third Bank of Kentucky for loan guarantees.

UCE - Harold Kleinert

Noted that the project Brighter Tomorrows has been funded by the National Center on Birth Defects and Developmental Disabilities to enable obstetrics/gynecology, pediatric, family practice residents, and currently practicing physicians to provide accurate, balanced information to families about Down Syndrome at the initial point of diagnosis. We will be developing two modules for physicians - one for informing the family of a diagnosis at birth, the other for informing the family in utero. The modules will allow residents and practicing physicians to simulate via CD an actual family encounter in which they have to provide the news of the child's disability. We are building on the technology that we have developed for the KY Preserve Health Training Project (Virtual Patient Project).

Noted with deep regret the death of one of our Core Team Members on the KY Preserve Health Training Project, Kevin Burberry. Kevin had a profound impact upon all those who knew him, and he proved that a significant disability did not mean that one could not accomplish a great deal in this world. Not only was he a member of the Core Development Team for these modules, he was also the actor for our first virtual patient case (the Bryan script). He completed filming for the Bryan case just two months before his death. His personal statement about the role of physicians in the lives of people with significant disabilities concludes the Bryan module; it is a powerful testimony about how physicians can make an important difference.

Kevin believed passionately in the right of each of us to full participation in our society. At the time of his death, he was completing his course work for his degree in Philosophy at the University of Kentucky, and was to graduate with high honors. He will be rewarded his degree posthumously. He was a founding member of the Kentucky Assistive Technology Loan Corporation and a member of the Board of Directors of the Bluegrass Technology Center.

Protection and Advocacy - Jeff Edwards

Over a 3-year period, P&A has filed complaints with the Office for Civil Rights, U.S. Dept. of Justice, against the state on behalf of 27 individuals. The complaints allege that the state is discriminating against the 27 because of its failure to provide services to them in the most integrated settings (Olmstead).

The 27 were living in public institutions - 20 in psychiatric hospitals, 6 in ICFs/MRs, and 1 in a nursing home.

26 had mental retardation and/or mental illness. One had physical disabilities.

17 had state guardians; 10 had private guardians or no guardians.

19 moved out of the institution (or are in the process of moving) into a more integrated setting (positive outcome) either as a result of the OCR complaint or while the complaint was pending.

2 people left the institution and OCR closed their complaints; however, the 2 are again living in institutions.

1 received funding for a community placement so OCR closed the complaint; however, the state rescinded the funding and we are appealing.

1 complaint was closed by OCR, which said the individual just had to wait.

2 were closed because the client changed her mind or was not able to give clear case direction.

2 are awaiting OCR action (I am optimistic that they will leave and move into community settings).

19-21 positive client outcomes as a result of filing OCR complaints. I believe that the funding for SCL slots that was in the budget bill and the wrap around money for people in psych hospitals was due in part to P&A's lawsuit and filing OCR complaints.

Non Profit - Holly Smith - Report given by Wanda Propes

The PUSH Early Childhood Center is seeing 100 children daily with various developmental delays in inclusive playsettings and in the community. Recently laid off 11 staff and closed 2 classrooms due to state cuts and general giving to nonprofits. Not able to access Federal funding. Holly resigned as director due to cuts and is now solely writing grants. There is currently a waiting list for children who have disabilities whose parents desire playtime with

typical peers. PUSH is now considering charging families of children with delays due to cuts.

Olmstead - Chastity Ross

DISCUSSION - Requested to be removed from the committee unable to attend. Marie Braun volunteered. Cabinet for Health Services will be notified to change. Haley reported that committee is meeting under a non-state chair meetings are short in duration. Some progress is being made in a final plan.

IHDI Project of National Significance Grant - Wanda Propes

Attended the Peer Tutoring Advisory Board meeting in September in Elizabethtown. Had a small group attending consisting of students with disabilities, their peers, teachers, administrators, and parents. The project has a website and it is up and running. Project is in its second and final year. We reviewed project accomplishments to date and shared project activities. Harold has asked for peer tutor volunteers to do peer tutor portfolios to pilot and have to him by December 1 to present to colleges.

Budget - Vicki Goins

DISCUSSION - The budget for 03-04 is in the meeting book. A total of \$41,465 was sent back to the feds. This money came from projects that did not spend all of their allotments.

AUDIENCE PARTICIPATION - None

ADJOURN

KLEINERT/WILLIAMS Motion to Adjourn at 2 p.m. MOTION PASSED

Next meeting is scheduled for February 12-13, 2004, at Embassy Suites in Lexington.