

**WV Developmental Disabilities Council
Meeting Minutes
Ramada Inn, South Charleston
October 28, 2003**

Members Present: Laura Helems, Robin Ayers, Tina Adams, Christy Bishop, Ophelia Coats, Craig Curtis, Karen Davis, Jeannie Elkins, Sandy Haberbosch, John Hunneshagen, Mary Ann Jenkins, Frank Kirkland, Clint Martin, Jane McCallister, Pat Moss, Libby Nester, Bob Peck, James Qualls, Bobby Reynolds, Terri Rodighiero, Kevin Smith, John David Smith, Jerri Stephens, Luann Summers, Cheryl Vega, Andrea Workman, Mary Ellen Zeppuhar

Members Absent: Richard Merryman, Jim Plitt, Keith Spencer, Dee Braley

Staff Present: Steve Wiseman, Jan Lilly Stewart, Jim Cremeans, Betsy Southall

Guests: Larry Medley, Bureau of Senior Services, Sally Burchfiel, WVU Center for Excellence in Disabilities, Jeannie Grimm, WVU Center for Excellence in Disabilities

Welcome, Introductions and Announcements

The meeting was called to order at 9:36 am by Laura Helems.

Members of the Council introduced themselves.

Craig Curtis read the *Mission Statement* of the Council.

Approval of the July 15, 2003 Minutes

Andrea Workman made and Kevin seconded a motion to accept the Minutes as written.

Motion carried.

New Business:

Legislative Priorities: Laura gave an overview of the proposed priorities for the upcoming legislative session outlined in the Council packets.

Community Supports

John David began a discussion regarding each state's legal obligation to have an ADA Coordinator. Several Members agreed that the legal mandate falls under the ADA stipulations.

Steve reminded State agency representatives that they may abstain from voting on the priorities which deal specifically with their agency.

Karen made and Kevin seconded a motion to accept the Community Supports Priorities.

Frank, Luann and Jane abstained.

Motion carried.

Health

Craig began a discussion on the previously proposed ATV legislation that would improve safety and which did not pass in the 2003 session.

Laura stated that the motorcycle helmet priority has been purposefully omitted from this year's Council priorities, but we will support the continuation of the law if it gets challenged during the session.

Sandy stated that she felt that MR/DD support workers need more money.

James made and Kevin seconded a motion to accept the Health Priorities as written and monitoring motorcycle helmet law if it arises.

Frank, Luann and Jane abstained.

Motion carried.

Employment

Steve corrected "FY 2004" to read "FY 2005" in the Supported Employment section of the draft priorities.

John David began a discussion on the Council's systems monitoring process during the legislative session.

Ophelia made and Kevin seconded a motion to accept the Employment Priorities as written.

Frank, Luann and Jane abstained.

Motion carried.

Education

James pointed out a spelling mistake on the Education Amendment to the draft priorities.

Mary Ann Jenkins began a discussion regarding protections needed for students with behavior support needs. She expressed concern about an education amendment which addresses the uniform discipline policies.

Sandy made and Karen seconded a motion to accept the Education Priorities as corrected.

Frank, Luann and Jane abstained.

Motion carried.

New Committee Assignments/Leadership: Laura gave an overview of the new Committee assignments. Assignments were made based on a Member survey.

Members briefly discussed the logistics of individual committee meetings. Steve reminded Members that they could participate in the meetings via conference call.

Update on Council Activities

Workforce Development Initiative: Jim C. gave an overview of the Workforce Development Initiative. He stated that there has been an ongoing crisis with direct care staff over the last several years. He stated that these workers are among the lowest paid workers. The workforce has been steadily declining over the last few years. The Council has contracted with Human Services Research Institute [HSRI] to work with stakeholders in developing a plan to improve direct support training standards.

The Council staff will meet with HSRI on October 30, 2003 at the Marriott to develop strategies for creating a direct support staff development curriculum and a long term strategic plan for WV.

Steve stated that there has been a tremendous positive response to this project from interested stakeholders.

Health Accessibility Survey: Steve gave an overview of the Health Care Accessibility study to be carried out by HSRI. The project will examine the health care needs and access to community health care by people in ICF/MR group homes and on the MR/DD & A/D Waivers in comparison to people who do not have disabilities. He stated that this project will add specific health related items to the Core Indicators Survey Project. Results of the study will be reported to the ADD.

Christy stated that there is a work group in the beginning stages of formation, but that the group has not yet met.

Libby stated that she questioned the validity of the Core Indicators Project. She said that her daughter participated in the project and she was not pleased with the interview process. The interviewers did not complete the full interview process, and failed to show up for the second round of interviews.

Kevin stated that his experience with the interviewer was more positive, and a discussion ensued.

Jim C. stated that the number of interviews had doubled from the first year. He said that he would look into how the interview process worked. He stated that one of the goals of the program was to continually improve itself.

Council Leadership Development: Laura stated that there would be a brief orientation for new Council Members at lunch. She gave a brief overview of the contents of the Council packets and new Member manual pages.

Steve gave an overview of the presentation made by Vicki Smith at the last Executive Committee Meeting. She is a national trainer for Developmental Disabilities Councils nationwide. She has also worked with other advocacy groups in WV, including the recent Partners In Policymaking (PIP) Reunion.

Laura stated that there will be a retreat on Feb. 6-7, 2004 to focus on Council leadership. Ms. Smith will be the facilitator at the retreat.

Utah Council and PNS Reviews: Laura reported that Pat Morrissey, Commissioner for ADD, recently asked Steve to go to Utah to facilitate a retreat for the Utah Council. The Council donated Steve's time, and Utah paid for his expenses.

Steve stated that the Utah Council was trying to shift the power within their Council from State Agencies having the majority of the power to having the people with developmental disabilities and family Members yielding most of the power. Steve worked to get the Council Members to understand the need for all Members to share equally in the power and responsibility. He felt that the experience was very positive for him as well as for the Utah Council.

Steve stated that he was also recently asked to be part of the review process for the Projects of National Significance (PNS) (Linda was originally asked, but could not participate due to a scheduling conflict). He spent a week in Washington, DC learning about the PNS process in case WV would ever want to apply for one of these grants.

Budget Update: Steve stated that the Federal Government has not resolved the budget at their level and therefore the Council has not received its allocations. He stated that the Council is operating under a loan from the DHHR until the allocation comes through. He stated it was good that the Council passed a conservative budget at the last meeting. We have not had enough cash to activate the FFY 2004 grants and meet operating expenses.

Training Initiatives

Steve stated that there are 4 major training initiatives that will take place this year. He said that there needs to be a very small workgroup for each of these initiatives.

Emergency Responders: Steve gave a brief overview of a project idea designed to train "first responder" personnel including police officers, fire fighters, EMTs etc., on how to respond appropriately to the needs of people with developmental disabilities in emergency and/or crisis situations. He stated that the Council has been promised \$28,000 by the Bureau of Behavioral Health and Health Facilities. The money will come from the State Disaster Relief Fund to help fund this project.

He stated that he received a proposal from a WVU for a study on post traumatic stress disorder (PTSD) in people with developmental disabilities. He said that the information gained from this project could be used in planning and setting priorities in the Emergency Responder Project.

Trusts, Wills and Guardianship: Steve stated that there is a relative lack of credible information regarding Trusts, Wills and Guardianship available to families and people with developmental disabilities. He would like to see the Council spearhead a training program to get credible and reliable information to families in WV. He said that he would like to see 5 or 6 workshops throughout the upcoming year.

Mary Ellen began a discussion of local and national contacts she felt would be good resources for this type of training. Members said that they would follow up and send their information to Steve.

Self Determination/Self Advocacy: Steve stated that there is a plan to do several projects around the state. John David began a discussion on the various trainings/workshops which have already been held in WV. Jeannie said that there is a great need for training and workshops on self-determination/self-advocacy for family Members and parents as well as for people with developmental disabilities, and a discussion ensued.

On the Outside: Steve stated that the materials and personnel are ready, and that he would like to see the program go into pilot schools. The focus for the program

is targeted at middle schools. He said that the program would start small in one or two schools and then branch out.

Steve asked the Council Members to volunteer to be on small workgroups for each project.

Mini-Grants: Laura stated that there had been some work on the standards, etc. for mini-grants. She stated that it has been a more complex project than expected.

Steve stated that he and the staff have been discussing possible parameters and guidelines for project proposal review, acceptance or denial. He would like to see organizations get small sums of money for projects which can make a big difference in their communities. He stated that all projects funded must be in support of the Council Mission and Vision.

Partners in Policymaking: Kevin Smith gave a brief overview of the PIP program, and began a discussion about the recent 10 year PIP Reunion held on October 10 – 11. He said that it was interesting to see how things have evolved and changed over the last decade and how people have put the principles from Partners to work in their lives. He stated that many of the boards he belongs to have Partners graduates sitting on them. He commended the Council for bringing the training to WV. He stated that he first met Ed Roberts, founder of the Independent Living Movement, at a Partners training in Texas. He stated that he was inspired to become involved in self-advocacy work because of his encounter with Mr. Roberts.

Jeannie, James and Karen gave an overview of their experience at the Partners reunion. Jeannie stated that the workshops were very informative and stated that it was a re-energizing experience for her. James stated that it was a very positive experience. Karen stated that there were only two graduates from her class and she wished there had been more in attendance.

PASS: Christy gave a brief overview of her recent participation in the Program Analysis of Service Systems (PASS) training in October. She said that it was a wonderful and intense educational experience for her.

Steve stated that PASS is a training program to evaluate social services from the perspective of the people who rely on the services. The Council partners with the BHHF, Developmental Disabilities Division to fund the project. The SILC and BoSS also contributed to the training by donating staff time.

Frank said that many of the participants who worked at the DD Division and went through the training thanked him for the chance to participate. He said that one individual said that it was a life changing experience for him.

Meeting dates/locations for next year: Laura stated that the locations of meetings for 2004 have been set. The new dates and meeting locations are attached.

State Programs and Initiatives

Aged/Disabled (A/D) Waiver: Bobby Reynolds gave an overview of the changes being made to the A/D Waiver. She said that one of the primary changes is that the Pre-Admission Screening (PAS) review will now be done by a private agency which will be West Virginia Medical Institute (WVMI). WVMI will start the PAS reviews on Monday, November 3rd. She stated that these changes will help ensure that all individuals on the program are completely eligible.

Bobby reviewed the changes to the A/D Waiver Manual which reflect some of the changes suggested by the advocacy community, including relaxing some rules on who can provide services. Now, only an eligible recipient's spouse is excluded from providing direct services. She stated that the new Manual is online. The address is www.wvdhhr.org/bms - choose "Provider Manuals." All users can use the site, although they must request a provider number. She also stated that there are several of the A/D Waiver forms on the Bureau of Senior Services site (<http://www.state.wv.us/seniorservices>).

Bobby said that the wait list for the A/D Waiver is 6 months long. Currently there are 1124 people on the wait list. Of that amount 277 are under 65 years of age, meaning that they have a disability.

Laura asked Bobby what advocacy groups could do to help. Bobby stated that there was nothing that could be done at this point. She said that the influence needs to come from within the system. She said that if advocacy groups can do something at a later date, she would let the Council know.

MR/DD Waiver: Frank gave an overview of the MR/DD Waiver. He stated that the program is not under a waiting list at the current time. Laura began a discussion about the 400 waiver slots that were approved for this year.

Frank said the focus of the program is now on re-staffing and on quality assurance. A Quality Council has been formed to monitor services. He stated that there are 7 positions in the Waiver program which are dedicated to quality assurance. He stated that they are in the process of using their new quality assurance tools, and he is pleased with the progress they are making.

Frank said that they are currently in the process of reviewing the current manual to make necessary changes. He said that there will be regional training on the new manuals when the codes are changed in compliance with HIPPA regulations.

Frank said that the Special Projects reimbursement is being eliminated. The individuals affected will be served under the fee for service codes with a prior

authorization process system for individuals who need to exceed either the \$6,400 per month cap or exceed specific caps for individual codes. He said that the time frame for this change was delayed, and the final switch from special projects fee for service with prior authorization will occur in February 2004.

Karen began a discussion about the qualifications and review process for MR/DD Waiver eligibility and opportunities for person centered planning within the Waiver program.

Mary Ellen asked what the wait time is from the time people apply to the Waiver to the time they receive services. Frank said he wasn't sure, but would look into it. Frank stated that consumers and families were welcome and encouraged to attend the Waiver Conference.

Birth To Three: Pat Moss gave an overview of the Birth To Three (BTT) program. She reviewed the new family driven/person-centered changes they have been making to the program. She described the new Regional Administrative Units which are designed to make the program more accessible to children and families throughout the state.

Pat stated that there is a lot of information about BTT program as well as provider information located on their website at www.wvdhhr.or/mcfh/birth23. Improvements to BTT include no limits on services provided, streamlining and simplifying the reimbursement procedures, strengthening training and expanding choice for families.

Steve commended the program for its move from a provider driven program to an individual or family driven program. He stated that the program should be held as a model for other programs providing services to people with developmental and other disabilities.

Mary Ann Jenkins began a discussion about the review process to deal with provider monopolies within the system, and the provider enrollment process.

Systems Change Grants: Jeannie Grimm of the WVU Center for Excellence in Disabilities gave an overview of the Real Choice Grant. Real Choice is a systems change grant aimed at improving long-term support systems for people with disabilities or long-term illnesses so that they can make their own choices and have the necessary supports to live and work in the communities.

Sally Burchfiel gave an overview of the C-PASS and TIC grants. The Community Personal Assistant Services and Supports (C-PASS) grant is a Medicaid funded grant. It is a systems change project to assist the State in making personal assistant services more affordable, flexible and self-directed. They are also working to create a Participant Manual to assist people in learning how to direct their own services. She stated that another focus of the program is

to train providers to make their services more self directed for the people who rely on the services.

The Transitioning to Inclusive Communities (TIC) grant focuses on moving money to the communities so that people can remain in the communities of their choice rather than having the money go into institutional models such as nursing homes.

WVA Priorities and Objectives: Bob Peck gave an overview of the WVA and what its duties are. The primary responsibility is to ensure that people with disabilities get to enjoy the rights enjoyed by people without disabilities. Please see attached.

Laura began a discussion on the possibilities of collaboration between WVA and the Council. Bob suggested working together to ensure that people with disabilities are able to vote. He mentioned the Help America Vote Act (HAVA) that mandates States upgrade their election procedures.

Jeannie asked how much work WVA has done in helping solve the problem of children being bussed out of their home school districts. Bob stated that he hasn't had a client through which to address this issue.

Announcements, Feedback Forms, Other

Steve read "Karen Davis's Story" written for a Stolen Life Campaign by ADAPT in Washington DC.

Laura announced that Steve has been appointed by Governor Wise to be a Commissioner on the WV Commission on National and Community Service.

Steve announced that the Council and the UCED are collaborating for a 2004 Calendar featuring positive images of people with disabilities.

James stated that he took part in the "Walk and Roll Parade" which took place in Huntington. He said that it was picked up by many local TV networks.

Adjournment

Ophelia made and Kevin seconded a motion to adjourn.

Motion carried.

The meeting was adjourned at 3:06 pm.