

WV Developmental Disabilities Council
Meeting Minutes
Summit Conference Center, Charleston, WV
October 24, 2006

Members Present: Jerri Stephens, Clint Martin, Christy Bishop, Kevin Smith, Christina Smith, Zila Schemel, Jeannie Elkins, LuAnn Summers, Kim Farley, Karen Ruddle, S. Craig Curtis, Frank Kirkland, Jeff Marr, Clarice Hausch, Richard Covert, Parul Shah, Christy Black, Ginny Gattlieb, Julie Shelton, Pat Winston, Jennifer Waybright, Mary Ann Jenkins, Cheryl Vega, Janice Holland, Pat Moss, Sandy Haberbosch, Bob Cain

Members Absent: Ron Dean, Jane McCallister, Libby Nester, Karen Robinson, John David Smith

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

Guests: Vanessa Van Gilder, Cassandra Toliver

Welcome, Introductions and Announcements:

The meeting was called to order at 9:48 am by Jerri Stephens.

Members of the Council introduced themselves.

Craig Curtis read the Council Mission statement.

Public Comments:

No comments offered.

Approval of the July 25, 2006 Minutes:

Kevin made and Christina seconded a motion to accept the Minutes as read.

Motion carried.

NACDD Conference

Jerri gave an overview of the participation of Council Members at the NACDD conference in Pittsburgh. She said that there was a lot of good information presented and WV was well represented.

Karen Ruddle said that everyone really enjoyed the keynote address by Patrick Schwartz. Dr. Schwartz is an Associate Professor of Special Education at National-Louis University, Chicago. Karen said that she purchased his book, From Disability to Possibility, and feels that it would be good as a book study.

Karen also said that she really enjoyed getting information on a project called "Able Lives," in which the Connecticut Council on Developmental Disabilities worked with Connecticut Public Television, American View Productions, and several state agency partners to create a series of 10 ½-hour video episodes called "Able Lives" on inclusion of people with disabilities in the community. It has aired monthly during prime time on Connecticut Public Television since April 2006. The series is reaching millions of viewers. In addition, a thirty second promotional piece about the Council is aired before highly popular shows. She said that any state can use the series Able Lives. Once purchased, the Councils could add their tag line.

Parul said that she felt that "Able Lives" was very powerful and a good tool for communities to use.

Clint said that he thought it was one of the most powerful presentations he had ever seen. He also said that the Council play *On The Outside* was also very powerful and that he was happy that the word is getting out there in a way that people can see it.

Jennifer said that she really enjoyed the conference. She said that she learned a lot from the presentations at the conference. She said she also enjoyed the *On the Outside* presentation.

Jerri announced that Howard Cobb, a gentleman who was featured in the On the Outside book, gave a brief presentation about his experiences in WV institutions and with the creation of the book.

Kevin said that he also felt that Patrick Schwartz was very dynamic and kept the audience motivated. He said he enjoyed many of the conference activities, including the boat ride.

Jeannie said that she felt the conference was a good experience. She said that she attended a panel discussion and felt that the WV Council shined in comparison to other Councils.

LuAnn said that she enjoyed a session called “Seeing with New Eyes” presented by Susan Yuan, Center on Disability and Community Inclusion, University of Vermont, Burlington, VT. The presentation addressed reactions when family members first learn of the disability of a child. It showed that the “Grieving Model,” which has dominated that process of interpretation, may be fundamentally incompatible with the positive perception of disability. This presentation described the results of a reframing exercise done with more than 2500 participants, who constructed new metaphors to describe their life experience.

Cheryl said that she saw a definite improvement in unity in the Conference itself. She feels that this was hopefully an indication of a greater unity throughout the disability community.

Christina said that she really enjoyed the *On the Outside* presentation but felt like it was preaching to the choir. She said she would like to take the presentation outside of the disability community.

Jan said that she felt that it was good to have it at the conference because she feels that some professionals don’t really believe that the atrocities that happened in the state institutions truly happened. Steve said that he hoped that the presentation would inspire other states to create similar projects in their states.

Jeff said that he really liked the location of the conference and that he learned a lot about independent living.

Zila said that she really enjoyed the conference experience and other activities including the boat ride.

Mary Ann said that she particularly enjoyed the keynote speaker. She said that Dr. Schwartz donated a copy of his book for her professional library at her school.

Bob said he thought the conference was very interesting.

Update on Council Staff Activities

Steve said that after the last meeting, the staff did all of the paperwork to get the new grant projects up and running. He said each grant for FY 2007 includes a Statement of Work, a more thorough project description that complies with DHHR contract requirements.

Steve said that staff traveled the state to meet with each of the grantees. He said that the monitoring structure has changed and that Linda will be handling compliance issues with grantees. Program staff will continue to negotiate milestones/goals and provide technical assistance to grantees.

Other activities that staff has been involved in include:

- Fairshake Network's Self-Determination Training – John XXIII Center
- APS's Training for Providers on MR/DD Waiver - Flatwoods
- DHHR's Money Follows the Person Conference Planning Call
- MR/DD Waiver QA/I Council Members meeting
- UCEDD's Direct Service Worker Support Workshop – Stonewall
- DHHR's College of Direct Support Presentation
- LOCHHRA meeting on A/D Waiver in House Chambers
- People First Conference – Canaan Valley
- Governor's Summit on Aging – Canaan Valley
- PIP sessions began Sep 15
- Site visits to grantees: MURC, Arc of the MOV, Easter Seals, REM, Clyde's Karate
- NACDD Conference, Pittsburgh
- Medical Ethics & Disabilities Workshop - Chas
- Protecting the Lives of Hospitalized Patients Workshop – Chas
- Money Follows the Person Stakeholder's Meeting – WV DRS

New Business:

Review and Discussion of Proposed Changes to Council By-Laws and relevant Policies

Jerri stated that all Members should have received a packet containing the proposed changes to the By-Laws and relevant Policies. Linda led a discussion on proposed changes to the Policies on Committees. The proposed changes incorporate workgroups on specific issues rather than the old committee structure. The Executive Committee and the Nominating Committee would be the only standing committees. She encouraged Members to review the changes and be prepared to vote on the changes at the January meeting.

Linda discussed the proposed changes to the By-Laws which include proposed changes to the structure of the Executive Committee. The Executive Committee used to be comprised of Council officers and the chairs of each committee. Since the committee structure would no longer exist, the Staff proposes that the Council itself elect 3 members from the Council membership to serve on the Executive Committee with the Council Chair and the Vice-Chair.

Janice pointed out that the By-Laws include the inclusion of the past chair on the Executive Committee which would raise the Committee to 6 individuals. Craig also pointed out that there is no indication of term length outlined in the By-Laws and a discussion ensued.

Christina began a discussion regarding the proposed workgroup structure. She asked for more specific clarification on how workgroups come into existence. Cheryl expressed a concern that there would be some Members who would not participate. She would like to have an assurance that State representatives and family members and people with developmental disabilities still come to the same table to work on specific issues.

Steve proposed forming a workgroup to help clarify and revise the changes in the Policies and By-Laws. The workgroup would help to revise the Policies and By-Laws and distribute the proposed changes to Members for vote at the January meeting. He said that the

workgroup would also be responsible for finding a way to elect new members to the Executive Committee at the January meeting.

Linda gave an overview of the proposed changes to the Policy on Grants. She said that the changes include the addition of language to reflect the change from committees to workgroups.

Jerri asked for volunteers to form a workgroup to address changes to the By-Laws and relevant Policies. Parul, Kim, Christina, Richard, Sandy, Jennifer , Bob and Pat Moss volunteered.

Legislative Priorities Work Group Report

Jeannie gave an overview of the workgroup recommendations regarding the 2007 Legislative Priorities. She stated the workgroup recommended carrying forward many of the 2006 priorities since many of the issues still need to be addressed. She outlined the suggested changes to last year's priorities (see attached).

Christina began a discussion regarding transportation issues. Jan said that transportation and accessible parking were not reflected in the draft priorities. She said that the Legislative committees responsible for those bills had not completed their work. She said that is one of the items that she will work on during the session but there was not enough information available to write a specific priority for publication.

Sandy made and Kevin seconded a motion to adopt the Legislative Priorities for the 2007 Legislative Session as presented.

Motion carried. LuAnn, Janice, Pat Winston, Julie Shelton, Frank, Karen Ruddle abstained.

Other Business

Next Year's Council Meeting Dates/Locations

Jerri reviewed the dates and locations for the 2007 quarterly Council meetings.

Jeannie pointed out that the January meeting is scheduled for the same day as the Fair Shake Legislative Training. The Council agreed to change the date for the January meeting to January 30, 2007 (see attached).

Review of FY 2007 Council Grants

Steve reviewed the current Council grants and gave an overview of the projects and responsibilities of each grantee. Grant projects for FY 2007 include:

Easter Seals Rehabilitation Center – Just completed work for FY 2006 after receiving a short grant extension. A training curriculum for childcare personnel and report on funding needs will be sent to the Council soon. Grant is now ended.

Arc of the Mid Ohio Valley - The Arc has two grants – 1) Health and Wellth, third year grant which seeks to increase access to community health and medical services for people with developmental disabilities, and 2) Inclusion for All which focuses on increasing participation by people with dd in community recreational, leisure, and social activities.

Clyde's Karate – First year funding for inclusive martial arts program in the eastern panhandle.

Dat2a – Grant to develop a self-advocacy organization specific to people with developmental disabilities.

Fair Shake Network – Cross-disability organization dedicated to self-advocacy and public policy change.

Marshall University/Care Coordination through Medical Homes – Third year grant that utilizes parents as care coordinators, supported by a multi-disciplinary team, to individualize planning/services for children with dd who have chronic health conditions.

REM Community Options – Third year of grant to develop a business led school to work program.

State Agency Members Informational Update

BHMF/DD Division

Frank stated that the Bureau has been looking at redesigning behavioral health. He said that the first report has been released from Public Consulting Group (PCG) and they are looking to contract with PCG to accomplish the 2nd part of the redesign.

He said that the new MR/DD Waiver Manual will go into effect November 1st. He said that the DD Division is involved in a new program focusing on employment for people with developmental disabilities. He said that WV is one of 13 states to be involved in this program. Employment will be a major focus of the DD Division in the upcoming year.

He said that the Department is continuing to work on the Core Indicators Project. The National Core Indicators Project is a consumer based satisfaction survey activity that is intended to be used to improve the delivery of supports and services for people with developmental disabilities. The Department has also released a new CFI for new crisis beds for children. Kristie Byrd is the new Crisis Services Coordinator at the DD Division. Kristie will assist providers in securing emergency placement for persons with developmental disabilities in behavioral crisis situations.

Frank introduced Cassandra Toliver as the new Family Support Coordinator. He said that he is very happy to have the position filled and have the Family Supports Program running again.

Bureau of Senior Services (BoSS)

Julie Shelton discussed the self-directed option implementation for the A/D Waiver. This option would give individuals who use this waiver greater choice and control over their services. She said that they are working on incorporating the self-directed option into the A/D Waiver manual. She said that the manual revisions should be available for public comment in the next couple of weeks. Interested individuals should check the BoSS website. She hopes that the Personal Options,

the official name of the self-directed option, will be available after the first of the year.

The Aging and Disability Resource Center (ADRCs) is a grant that BoSS received from the federal government. The grant created two Aging and Disability Resource Centers in WV. The Bureau has received additional funding and they are expanding the existing two ADRCs. They anticipate that there will be additional ADRC's created with State funds.

Maternal, Child and Family Health

Pat Moss said that they are working at the legislative level to expand the Metabolic Screening Services. Currently, WV only screens for 6 disorders. The goal is to meet the federal standards and screen for 28 metabolic disorders. The additional tests will be billed to private insurers rather than paying for the tests from public funds.

Bureau of Medical Services (BMS)

Pat Winston said that Medicaid will be undergoing a re-organization over the next several months. BMS will be split into 2 programs – Finance and Policy. She said that the program of most interest to the Council is the Policy Program. The Policy program will be split into 5 divisions:

- 1) Community based services – Pat Winston
- 2) Practitioner/Outpatient services – Pat Wood
- 3) Hospitals and residential facility services - TBA
- 4) Pharmacy Services – Peggy King
- 5) Contracts - TBA

Pat said that it is the intent of BMS to take the MR/DD Waiver program into the self directed option. She said that they will begin working on that after the re-organization.

Pat said that they are working on setting the rates for the “level 2 codes.” She explained the different factors for setting the rates and said that the methodology and process was available on the BMS website at www.wvdhhr.org/bms

Kevin began a discussion regarding assuring that direct care staff will receive benefit from the increase in rates for those services. Pat said that BMS does not have the authority to control personnel issues.

Division of Rehabilitation Services (DRS)

LuAnn said that there is still a waiting list. She said that people should still send in referrals.

LuAnn said that Virginia Commonwealth University got a contract to set up training based for Community Rehabilitation. Council staff are actively working with VCU, DRS, and DD Division personnel on expanding employment options.

West Virginia Advocates (WVA)

Clarice announced that WVA has just opened a 2nd office in Bridgeport. She said that WVA is focusing on employment and has hired Suzanne Taylor to focus on employment issues.

Other Updates from Members

Medical Ethics & Disabilities Workshop

Steve said that this workshop was a collaboration with WV Network of Ethics committees, SILC, FSN, UCED, Alzheimer's Association, Nursing Home Providers Association and the WV DDC. He said the workshop was well attended and successful. He said that Council staff, Members and past Members participated in the panel discussion. Kevin discussed his experience on the panel.

Christina discussed her participation on a panel as a caregiver of a person with a disability. She said that she felt that healthcare professionals do devalue the lives of people with developmental disabilities.

Protecting the Lives of Hospital Patients Workshop

Linda discussed the Protecting the Lives of Hospital Patients Workshop. The Council invited Jo Masserelli and Joe Osburn to present in combination with the Medical Ethics workshop because of the relevancy and correlation of the topics.

This workshop focused on the overall devaluation of lives of vulnerable individuals. Christy Black discussed her participation on a panel as a parent of a child of a disability.

Kim asked if there had been any contact from participants after the workshop was over. Steve said that participants were asked to fill out evaluation forms and the evaluations were positive. He also said that Jo Masserelli had complimented WV on hosting this type of workshop given the controversial nature of the topics.

Grantee Presentation – Fair Shake Network

Vanessa VanGilder, Coordinator of the Fair Shake Network (FSN), provided an overview of the history, mission, training and activities of the FSN. She said that the FSN is the only statewide cross disability advocacy network in WV. She invited Council members to attend FSN meetings if they are interested and gave them information on how to join the organization.

Vanessa said that FSN will be working with Vicki Smith (Dat2a) on the Council's self advocacy initiative. The FSN is working on developing their disability legislative agenda. The group will host two trainings this year. One will be on legislative advocacy and one will be on employment. The FSN plans to host Disability Advocacy Day and Transportation Day at the Legislature. She distributed information with dates for the two days at the legislature and the scheduled trainings.

Announcements

Jerri reminded Members that the January Council meeting has been changed to January 30, 2007.

Adjournment

Frank moved and Jeannie seconded a motion to adjourn.

Motion carried.

The meeting was adjourned at 3:11 p.m.