

WV Developmental Disabilities Council
Quarterly Meeting
Country Inn & Suites, Beckley, WV
July 28, 2015

MINUTES

Members present: Doug Auten, Greg Bilonick, Jonathan Chaffin, Joyce Church, Deborah Davis, Clarice Hausch, Amber Hinkle, Betty Holliday, Betsy Peterson for Pat Homberg, Ann Hubbs, Rickey Meade, Kelly Miller, Beth Morrison, Pat Moss, Mekell Golden for Christina Mullins, Pat Nisbet, Clark Queen, Jerry Ramsey, Jon Sassi, and Jenni Sutherland.

Members absent: Brent Bush, Stefanie Caldwell, Pat Elliott, Mary Etta Jones, Jane McCallister, Wanda Proffitt, Tara Roush, Tina Tanner, Stacey Thomas, and Melvin West.

Staff present: Christy Black, Jim Cremeans, Linda Higgs, and Steve Wiseman.

Guests present: Rose Lowther-Berman (BMS), Samantha Robinson (BHFF), Stephanie Thorn (WVA), Cassandra Toliver (BHFF), Ruth Vance (BoSS intern) and pending new Members: Angie Breeden, Julie Dial, and Kristin O'Neal.

Call to Order, Welcome: Deborah Davis called the meeting to order and welcomed everyone.

Introductions and Announcements by Members: Deborah asked Members to introduce themselves, followed by a request for any announcements. Kelly announced that her daughter's health has improved following her weight loss. Steve announced that the final rules for the DD Act (of 2000) have just been approved. More information may be provided at the next meeting, if necessary, following a review of the rules.

Introductions and Comments by Those Awaiting Appointment: Deborah invited the guests who are awaiting appointment by the Governor to introduce themselves and share how they learned about the Council and why they were interested in becoming a Member.

Mission Statement Reminder: Ann Hubbs read the Council's Mission Statement.

Public Comment: None

Approval of April 22, 2015 Meeting Minutes: After reviewing the *Minutes*, Pat Nisbet requested a change be made on page 7 of 9 to reflect that the Bureau for Medical Services (BMS) is allowing settings for four people. Since this occurred following the April meeting, it was agreed the *Minutes* would not be changed, but a sentence would be included to reflect the change has since occurred. **Jonathan made a motion that the *Minutes* be accepted with the clarifying sentence and Greg seconded the motion. Motion carried.**

New Business

Approval of FFY 2016 Budget: Steve reviewed the budget information in Council Members' packets. He advised the Members that State employees have not received raises but that the cost of benefits will increase. He also reminded them that the Council's federal allotment is going down again. Councils were advised to plan for a flat budget but the US Senate HELP Committee is planning another cut, so whether or not the allotment remains the same is not yet known. The budget figures presented represent a plan for level funding. It includes a slight increase for current expenses.

Deborah called for a motion to approve the budget as presented. **Greg made a motion to approve the budget of \$755,914 for FFY 2016 and Joyce seconded the motion.** During discussion, **Ann pointed out a \$1200 discrepancy and moved that it be fixed. Betty seconded the motion and the motion carried.** **Then Members voted on the original motion to approve the budget and the motion carried.**

Steve then explained the two grants included in the budget that were approved by the Grant Review Workgroup which support DD Council functions in carrying out the Comprehensive State Plan and Council Member Support – Community Access, Inc. (CAI) and Mountain State Centers for Independent Living (MtStCIL).

Deborah called for a motion to approve the grant to MtStCIL. **Greg made a motion to fund the grant at \$139,370 and Clark seconded the motion. Motion carried.**

Deborah called for a motion to approve the grant to CAI. **Jonathan made a motion to fund the grant at \$215,417 and Kelly seconded the motion. Motion carried.**

Approval of Designated Stipends: Clarice Hausch reported on behalf of the Designated Stipends Fund Workgroup. Information on the proposed funding was provided in Council Members' packets. Proposed funding was:

Arc of WV, Youth Self Advocacy Conference - \$2500

Arc of WV, People First Conference - \$9000

Fair Shake Network, Training Day and Disability Advocacy Day - \$4500

Family Support Program, Families Conference - \$8000

WV SenseAbilities Project, CVI Workshop - \$2200

WV SenseAbilities Project, Family Learning Weekend - \$2200

Clarice made a motion on behalf of the Workgroup that Designated Stipends be funded as presented for a total of \$28,400. Joyce seconded the motion. Motion carried.

Approval of Renewal Grants: Jenni reported on behalf of the Grant Review Workgroup. Information on the proposed funding was provided in Council Members' packets.

Jenni made a motion on behalf of the Grant Review Workgroup that the Arc of the Mid-Ohio Valley be funded at the requested amount of \$24,748. Pat Moss seconded the motion. Motion carried.

Jenni made the motion that the Arc of WV be funded at the requested amount of \$79,479. Greg seconded the motion. Motion carried.

Jenni made the motion that the Fair Shake Network be funded at the requested amount of \$21,000. Johnathan seconded the motion. Motion carried.

Update on I/DD Waiver and explanation of Alternate Benefits and Services available to individuals impacted by a reduction in Waiver Services: Pat Nisbet informed Members that the Centers for Medicare and Medicaid Services (CMS) has approved the Traumatic Brain Injury (TBI) Waiver application as of the previous Thursday (7/23) and has signaled that they are ready to approve the Aged and Disabled (A/D) Waiver application. She explained that BMS had answered all the questions from CMS on the Intellectual and Developmental Disabilities (IDD) Waiver the previous day (7/27). CMS has until August 8th to approve the application, but BMS has been granted an extension of the current waiver through

September 28th. She reported that most of the questions were financial, which she does not handle. A big question was concerning the lack of independent service coordination, which has been added. Agencies must have a “firewall” so their service coordinators do not steer Waiver recipients to residential services offered only by the agency for which they work. In response to a question about independent service coordination, Pat replied that the PAIS agency currently offers independent service coordination in three locations.

Pat reported that CMS does not require public comment on the Policy Manual, but BMS does. She also indicated it will not do any good to comment on issues that have been approved by CMS in the application.

She said that the proper terminology is “denial of services,” rather than “reduction in services.” She explained that budgets are determined through the assessments done by APS Healthcare and that the algorithm also takes historical claims information into account. She reported that most of the time budgets are raised rather than lowered. She also stated that the Waiver was over budget by \$55 million last year and that everyone must stay within their budget.

She then provided information about another way Waiver recipients might be able to get needed services and provided a handout from Chapter 517, Section 517.22.2, Personal Care Services.

Pat reported that as more people move to Individually Staffed Settings (ISS) due to aging parents there will be less money available for those living with their families.

Other information included: the average institutional cost (Intermediate Care Facilities for the Intellectually and Developmentally Disabled, or ICF/IID) is \$121,000; currently, 66 people on the I/DD Waiver are also billing Personal Care Services; the 2:1 staffing code is changing from one hour billable units to 15 minute units; the 2:1 code is for crisis services.

Other suggestions provided by Pat included: using school services for PT, OT, Sp/L, and Dietary services for school aged children, adults can access those services through State Plan services; use Non Emergency Medical Transportation (NEMT) for travel to/from doctor appointments; look at the “trips” being billed by agencies for Day Habilitation. Also, look at nursing services being provided and consider whether those services might be provided by an Authorized Medication Administration Personnel (AMAP). RN services often are not required, but some

Waiver recipients are still receiving the service. Some agencies bill the maximum of Behavior Support Professional (BSP) services for Waiver recipients, which may not be needed. Individuals can look to see what is being billed for Service Coordination services to determine if less could be used – a monthly home visit and two IPP meetings a year are required. Another suggestion was to look at using self-direction rather than agency services for respite care since the cost is about half through self-direction. The issue was raised that individuals do not know what is billed through their Waiver program, so Pat suggested asking the Service Coordinator to bring a print-out of the Utilization Management Report to each home visit.

In response to a question about the cost of paying APS Healthcare, Pat responded that the contract costs for the I/DD Waiver portion are \$867,000.

Pat introduced Rose Lowther-Berman as the state-wide Transition Plan Program Manager. Rose then spoke about the Transition Plan for the I/DD Waiver. The end dates for the transition time-frames has been changed from June, 2020 to March, 2019. She reported that Member surveys have been completed and Provider surveys are due on Friday (7/31). BMS will use the CMS toolkit to determine which programs meet the Home and Community Based Settings (HCBS) rule. They will initially be looking at day habilitation programs, and then residential settings. They will only review programs owned or leased by provider agencies.

Clarice raised a question related to any plans there might be in the transition process to train DHHR guardians. She believes there is a problem between OHFLAC rules and the CMS guide related to locked spaces. Pat responded there is not currently a plan to do so, and that the Behavioral Health Licensure Rules are currently being reviewed.

Abuse/Neglect workgroup report: Ann Hubbs reported on behalf of the workgroup. Discussion notes from the July 10th meeting of the Workgroup were included in Members' packets.

Update on Family & Community Support Program: Samantha Robinson and Cassandra Toliver attended the meeting and reported on the Family and Community Support Program. They provided handouts for Members. Samantha reported that the new program is about maximizing the use of community resources and they are in the process of helping service coordinators be more

aware of available resources. The Families Conference is being held November 6-8 at Canaan Valley Resort. The theme will be about what resources exist.

Cassandra reported that, in an effort to have the Council take a more active role in planning and conducting the conference, Melody Waybright was asked to take the lead on planning the conference. Cassandra and Samantha will provide support, rather than the Bureau planning the conference themselves. Cassandra mentioned a program for providing bikes to children with disabilities that they were asked to partner with the UCED to organize.

Pat Moss advised that Variety the Children's Charity, located in Pittsburgh, PA, which provides adaptive bikes to children with disabilities will expand their service area to ten WV counties – Barbour, Doddridge, Harrison, Marion, Marshall, Monongalia, Ohio, Preston, Taylor, and Wetzel. The plan is to use Family Support Coordinators to assist families in learning about the program and to help with filling out applications, etc. Pat envisions four physical therapy program sites will be distribution hubs for the bikes and has currently located three. The physical therapy sites will also be able to provide technical support to ensure the proper fit, as each bike is built specifically for each child. Families who are over income guidelines, or do not reside in the ten county area, will be referred to the charity for further consideration.

State Plan update: Jim Cremeans provided an update on the State Plan. He informed Members that Council staff are currently in the Comprehensive Review and Analysis (CRA) phase. The current Plan was developed primarily from the direct input of people with developmental disabilities and families. Four areas that must be addressed in the CRA in development of the State Plan are: Health/Healthcare; Employment; Informal and Formal Supports (includes long term care and other services including Olmstead, Family Support, Specialized Family Care, and the status of ICF/IID facilities); and Interagency Initiatives such as Council membership on the WV Early Intervention Interagency Coordinating Council (WV EICC), and WV Assistive Technology System (WVATS). Also, each Council must directly fund something in the area of self-advocacy, cross-disability coalitions, and training.

New State Plan workgroup report: Kelly Miller reported on behalf of the State Plan workgroup. Discussion notes were included in Members' packets.

Members' Concerns: Ann expressed her concern about the recent public comments about the I/DD Waiver and parents. Some of them make it seem as though families of children with significant disabilities are not “real families.” She feels parents of children with uncommon disabilities have learned things that could and should be of value to the state systems, and they could be great resources to them. She encouraged Member agencies to use the Council; she believes the Council is the voice of parents who have children with developmental disabilities. Deborah reported that the Council was actually contacted by legislators for information regarding the I/DD Waiver issues. She also reported that a previous graduate of the Council’s Partners in Policymaking program (PIP), Tracy White, successfully organized a rally about the cuts to the program. She then reported that Tracy has recently been hired as the new Coordinator of the Fair Shake Network.

Kelly expressed concern that the State is going backwards by spending more money to support group settings and less for family settings.

Jonathan expressed his concern that there are not as many people who seem to be interested in getting involved when issues other than the I/DD Waiver program need to be addressed.

Clarice reminded everyone that there are many people with severe disabilities who have no family to speak on their behalf whose services are also in jeopardy, and that there are over 1,000 people on the wait list for services.

Greg suggested a video to tell Members’ stories and concerns of how the changes will affect them, similar to the videos the People First grant does for its members.

Betty suggested such a video could be linked to the Council’s webpage.

Clarice reported that, after three years, she has been able to hire a new employee to do monitoring and advocacy in ICFs/IID. She has also hired a new Program Director, Stephanie Thorn, who attended the meeting.

Farewell to Members with expiring terms: Deborah and Steve gave certificates to Joyce Church, Ann Hubbs, Rickey Meade, and Jerry Ramsey, whose terms expire when the Governor makes new appointments. The other Member whose term will expire, Stefanie Caldwell, was absent. Cake was served.

Partners in Policymaking (PIP) update: Christy provided Members an update on the upcoming PIP session that will begin in September. The Council PIP Workgroup will meet on Thursday (7/30) to review applications and choose applicants eligible to attend. Christy reported that we have received 34 applications. The Council also has received scholarships from the WV Statewide Independent Living Council, The Olmstead Council, and WV Birth to Three. Christy discussed the speaker schedule for the upcoming program. She is looking forward to another successful program.

The Americans with Disabilities (ADA) and *Olmstead* anniversaries: Steve reminded Members that Sunday, July 26th was the 25th anniversary of the signing of the ADA by President George H.W. Bush. The ADA has and will continue to help millions of Americans gain a physical presence in the community. It has raised the consciousness of society about the existence and civil rights of people with disabilities to be included in the mainstream, and raises the expectations of people with disabilities themselves. Without the Federal law, it is hard to imagine that states and businesses would have made so many accommodations.

He also reminded Members that June 22nd was the 16th anniversary of the U.S. Supreme Court *Olmstead* decision. That ruling stated that services must be provided in the “most integrated settings.” The Department of Justice has stepped up enforcement in recent years. It is the basis of the new Home and Community Based Services Rule by CMS.

Steve went on to say that we are also aware that we cannot legislate or make rulings that will by themselves cause people with developmental and other disabilities and impairments to attain “the good things in life” that most members of our society take for granted – a real home, choice and control in life decisions, health and positive relationships – the typical, yet critical to having a full life.

Completion of Feedback forms: Deborah reminded Members to complete the Council feedback forms prior to leaving.

Adjournment: Kelly moved and Jenni seconded the motion to adjourn the meeting. The next meeting will be held on October 27, 2015, at the Blennerhassett Hotel in Parkersburg, WV