

WV Developmental Disabilities Council
Quarterly Meeting
Bridgeport Conference Center
April 22, 2014

MINUTES

Members present: Greg Bilonick, Brent Bush, Kathy Butler, Jonathan Chaffin, Joyce Church, Patricia Elliott, Clarice Hausch, Amber Hinkle, Betty Holliday, Ann Hubbs, Mary Etta Jones, William Rickey Meade, Kelly Miller, Beth Morrison, Pat Moss, Christina Mullins, Pat Nisbet, Sheila Paitsel, Wanda Proffitt, Clark Queen, Jerry Ramsey, Jenni Sutherland, Tara Roush, Jon Sassi, LuAnn Summers, Tina Tanner, Stacey Thomas, and Melvin West

Members absent: Sarah Brown, Stefanie Caldwell, Deborah Davis, and Jane McCallister

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

Guests: Christina Smith, Arc of the Mid Ohio Valley

Welcome, Introductions: Stacey invited everyone to introduce themselves.

Announcements: Steve announced that Nora Baladerian, a consultant to the Council from Los Angeles on sexual abuse of people with developmental disabilities, would be posting on her blog today that the WV DD Council is the leading Council in the nation on addressing the issues of sexual assault and people with developmental disabilities.

Kathy announced she is retiring effective June 30th, and will make recommendations for a Higher Education representative to replace her.

Pat Nisbet announced she has a new granddaughter.

Clark announced his sister is having a baby (her third).

Stacey expressed her regrets over her resignation as Chair of the Council and informed the Members that she intends to continue to fulfill her term as a Member.

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

Public Comments: None

Approval of October 22, 2013 Minutes: Clarice clarified that, on page 5, under PABSS, the statement should read “WVA can only help people with the first three administrative levels of appeals.”

Pat Nisbet requested that, on page 6, the first sentence, “Live-in workers are classified as general contract workers and agencies don’t have to pay them overtime.” be struck.

Melvin moved and Greg seconded the motion that the Minutes be approved as corrected. Motion passed.

Approval of January 28, 2014 Minutes: Ann asked that, on page 9, the sentence be corrected to read “Mandates that the person centered planning process be directed by the individual and may include a representative freely chosen by the individual.”

Brent moved and Greg seconded the motion that the Minutes be approved as corrected. Motion passed.

Before continuing on, Steve reminded Members that they were encouraged to stay at home rather than attend the January quarterly meeting and their absence will not be counted against them. He also informed Members that Michelle Norweck, who is in the current Partners in Policymaking class, was hired as the new Director of the Fair Shake Network.

Budget Update: Steve gave a mid-year update on the current budget. He reported that the line items for Personnel, Current Expenses and Equipment, and Grants and Contracts, are all slightly under budget.

The contract for the completion of the video for the Affordable Care Act was awarded to West Virginians for Affordable Health Care (WVAHC). They will complete the project for \$10,000.

The Council’s only new grant this fiscal year (to the Arc of the Mid-Ohio Valley for the self-protection initiative) is small, \$28,620.

Sequestration affected the Council's ability to spend money on new grant projects due to a \$50,000 decrease in the budget. It is anticipated that Councils will be funded at the same level in the next fiscal year.

LuAnn and Pat requested that Members receive written budget information prior to voting. Steve stated a full budget presentation would be made at the July meeting.

Designated Stipends Allotment: Steve reported that the current allotment is \$32,000 and recommends the same amount for the next federal fiscal year.

Melvin moved and Clark seconded the motion that \$32,000 be set aside for the funding of designated stipends in FFY 2015. Motion carried. LuAnn abstained from voting because written budget information was not provided.

Call for Investments Allotment: Steve recommended \$50,000 be made available for the Call for Investments.

Greg moved and Joyce seconded the motion that \$50,000 be set aside for the Call for Investments for FFY 2015. Motion carried. LuAnn abstained from voting because written budget information was not provided.

Election of Council Chairperson: A ballot vote was not necessary since only one Member submitted their name for consideration as Chair. **Brent moved to elect by acclamation Deborah Davis as Council Chair to complete the term of Stacey Thomas, who is resigning. Tara seconded the motion. Motion carried.** Deborah's term will be effective immediately and will expire June 30, 2015.

Election of Executive Committee Members: Election was delayed until after Workgroup reports to allow for Deborah's name to be struck from the Ballot.

Workgroup Reports

Employment First Workgroup: LuAnn reported for the workgroup since the Chair, Jon, was unable to attend the April 4th meeting. Notes from the meeting were in Members' folders. David Hoff, Program Director at the Institute for Community Inclusion, attended the meeting by phone to offer advice to the group about future plans.

LuAnn would like to see WV carry out some related activities before developing a new employment policy because policies often get developed and then put on the shelf.

Clarice was impressed with David's understanding of the cultural challenges in WV, including the need for families and people with developmental disabilities to understand the value of work.

Sheila will be participating on the workgroup, representing the WV Department of Education (DoE). She reported that Policy 2510 had been open for comment. It includes a career option component for students with disabilities. She also mentioned the IWork program is another option. The DoE is working to make some different paths to obtaining employment for people with developmental disabilities.

Stacey mentioned that Berkeley County has a good transition program for students, but that the ideas need to begin much earlier than the mandated transition time frames.

Executive Committee Members Election: Ballots for the replacement of two Executive Committee Members whose terms were expiring (Jerry and Jane) were distributed, collected, and tabulated. Those being elected to fill two year terms on the Executive Committee were Jonathan Chaffin and Christina Mullins. Terms are effective July 1st and will expire on June 30, 2016.

Abuse/Neglect Workgroup: Ann Hubbs reported for the workgroup. Notes from the meeting are in Members' folders. Ann reported how alarming it was to her when she learned the abuse rate for people with developmental disabilities was over 50% and feels that parents need to know, including knowing what to do when they realize their child has been abused.

An identified barrier was the lack of valid data for WV. It is hoped that the Council's grant, the self-protection initiative, can help with data.

Jim reported that the workgroup put together a set of recommendations for the I/DD Waiver renewal sub-committee on this topic in February. Next steps may include coming up with more recommendations at the next workgroup meeting. The workgroup wanted to get timely recommendations out for the Waiver renewal.

Steve stated that the report given by the Chair of the I/DD Waiver renewal abuse/neglect workgroup mostly consisted of the recommendations made thus far by the DD Council's own workgroup. The report was well received by the Quality Improvement Advisory (QIA) Council.

Status of new Medley Contract: Clarice reported that WV Advocates became the contractor for the Medley/Hartley Advocacy Project (MHAP) on January 1, 2014. The State contract was not signed until January 4th, so they were unable to order equipment or hire people early, as had been suggested. Staff for the project were hired by February 1, with one other hired on March 1. The office has been moved to Bridgeport.

The MHAP now has an electronic database that includes every Medley Class member, along with an inactive/deceased database. At least a dozen previously thought to be served were actually deceased. All staff received five hours of training and are scheduled for 40 hours of mediation training in Morgantown. All behavioral health centers, service coordinators, guardians, and Medley members have received packets of information about the project.

Steve asked Clarice to provide Members a brief overview of what constitutes a Medley Class member. The Medley Class was established as the result of a class-action lawsuit that closed institutions and mandated community services. To be a Class member, an individual must be institutionalized in state 30 days or more before the age of 22, and be born after 1956.

New members typically qualify as children who were sent to out-of-state facilities for services, come back at age 18, and, receiving no services, deteriorate and end up in a diversion hospital. If they are hospitalized for 30 days they then become a Medley Class member.

As of the end of March there were 363 active Class members. The majority live with their natural families, in intensively staffed settings (ISS), or in intermediate care facilities for the intellectually and developmentally disabled (ICFs/IDD). Several Class members are not on the I/DD Waiver, and live in specialized family care (SFC) homes, a small number live in nursing homes, and about 10 are in-patients at psychiatric hospitals. Two are in jail or prison. Four to six members

are out-of-state, and therefore inactive. Some choose to receive no services from the system.

The majority of Class members are going to day programs or sheltered workshops. Very few are receiving supported employment services.

Clarice feels this will be a good, reliable, sub-set of people with developmental disabilities for which data will be available to collect and analyze the experiences of people in WV.

The Hartley portion of the project includes people with developmental disabilities who are also at risk for institutionalization because of a co-occurring diagnosis of mental health or substance abuse issues.

The MHAP is also trying to establish a more definitive “unmet needs” database, possibly something that will show systemic/regional/unique to provider/unique to individual issues.

Clarice reports they are seeing the typical dental and other unmet needs, and some issues they see as violations of people’s rights.

Grantee presentation – Self Protection Initiative, Arc of the Mid-Ohio Valley:

Christina Smith provided the Council an overview of the newest grant related to the abuse and neglect of people with developmental disabilities. She provided statistics from the SafeGuard Project, which reported that over 70% of people surveyed reported they had been abused. Nearly 50% of those did not report, and of those who did report, around 54% said that nothing happened when they reported.

The project is using components of the Curriculum on Abuse Prevention and Empowerment (CAPE) and from Stop Abuse for Everybody (SAFE), which is a product from the PA DD Council.

The project includes evaluation and planning tools, including Working Together – a checklist used to determine vulnerability. They have developed a guide which included goals on safety/abuse/neglect that can be pulled and included in IPPs, IFSPs, IEPs, etc. Posters have been developed to be placed in schools, group homes, and other locations

Training on abuse/neglect is being incorporated into all People 1st meetings. The in-depth trainings are set to begin later in the week.

Update on I/DD Waiver renewal: Pat Nisbet reported that the Waiver had overspent its budget last year and she is beginning to look at ways to reduce costs in the renewal. Things being looked at include: parameters for one person ISSs; respite care; lowering some rates, such as behavior support professional rates; and enhancing supported employment rates.

14% of waiver recipients are self-directing. There are 654 people on Personal Options as of the end of March.

Surveys were sent to day program and residential sites. The Bureau for Medical Services intends to do more questionnaires and site visits.

The contracts for utilization management (APS Healthcare) and fiscal employer agency (PPL) are coming up for bid this year. The Bureau is trying to decide between a government model and a vendor FEA model. The vendor model could include hundreds of agencies, not necessarily behavioral health agencies.

Regarding the IRS Difficulty of Care letter, Pat stated that whether or not someone qualifies for the “difficulty of care” federal income tax exemption depends on total family income.

Regarding the State Plan Amendment for school-based health services, Pat stated schools can only bill on days specialized services are actually being provided.

On July 1st, the last 100 *Benjamin H.* slots will be released. There are currently 80 roll over slots that will also be released on July 1st, and there may be more by then. There are 4,634 people on the I/DD Waiver and currently 943 on the waiting list.

There are around 35 people on the TBI Waiver, and the Bureau is considering opening the program up to people under the age of 18 who qualify.

Pat Elliott asked if both parents can bill the I/DD Waiver for service provision. They may be able to, but it depends on whether or not one parent is the person who signs off on time sheets. If so, they both cannot bill.

Brent asked if there is a way to fund what people need, and fund “function” rather than billing minutes of service.

Ann remarked that reimbursement rates are the same despite varying levels of ability of Waiver recipients, and that those providing the services are often paid minimum wage. Pat stated that the reimbursement rate is \$20.04/hour, and that the Bureau cannot control what agencies pay.

Joyce added that 21 hours is not a lot for someone who needs 24 hours of care. People quit working and paying taxes in order to provide the services to someone and now services may be cut.

Steve commented that those who provide the services are not State employees, and “competition” has not driven up quality.

Pat advised that two agencies, Logan Mingo Mental Health and the Arc of the Three Rivers have told families they will no longer employ them. They were still employing family members as contractors, rather than as employees.

Final Legislative Report: Christy provided Members with a final report of the legislative session. She mentioned there were 1,876 bills introduced and 201 bills passed. The Governor vetoed eight of those bills that passed.

Highlights included in the Budget Bill (SB 306):

- Independent Living was restored to \$500,000
- Family Support was cut from \$985,078 to \$251,226
- Center for Excellence in Disabilities was cut from \$318,701 to \$310,701
- Aged and Disabled (A/D) Waiver received an increase, from \$10,131,368 to \$19,457,690, which was vetoed by the Governor. The A/D Waiver then received an increase to \$15,597,690.
- I/DD Waiver funding remained the same at \$88,753,483
- Birth to Three funding remained at \$22,399,982
- Behavioral Health Programs received an increase from \$67,447,913 to \$75,181,543

SB 397 passed and expands the scope of activities considered financial exploitation of the elderly. It also pertains to protected persons and /or incapacitated adults.

The expansion includes undue influence, fraud, deception, intimidation, extortion, embezzlement, forced threat, etc.

HB 4244, pertaining to sedating persons when placed in a four point restraint did not pass.

HB 4287, the AMAP bill, to add trach and vent care to the list of health maintenance tasks that can be provided by an approved medication assistive personnel (non-medical professionals) passed.

SB 209, which allows special education students to participate in graduation ceremonies with their peers, when requested by their parents, and then continue receiving special education services until age 21 passed.

HB 4384, requiring teachers to either be present at IEP meetings or to read and sign a copy of the IEP passed.

SB 2 and HB 2276, which would have provided tax incentives to dental practitioners performing services to indigents, did not pass.

Update on Council Activities

National Disability Policy Seminar: Kelly reported that she, Stefanie, Christy, and Steve attended the seminar in Washington, DC which was held April 7-9. They met with the State's Congressional representatives and talked with them about several pertinent issues, including protecting the individual entitlement to Medicaid and Medicare; the reauthorization of the *Elementary Secondary Education Act*; the importance of regulations concerning seclusion and restraints in the *Keeping All Students Safe Act*; the reauthorization of the *Developmental Disabilities Bill of Rights Act*; and the reauthorization of the *Workforce Investment Act*. Kelly expressed her appreciation for being invited to attend on behalf of the Council and felt it was a good experience to be able to attend and to meet other parents from around the country.

Christy added that the Policy seminar is a joint meeting of several national organizations, including the National Association of Councils on Developmental Disabilities (NACDD), United Cerebral Palsy (UCP), The Arc, the Association of University Centers in Disabilities, Education, Research, and Service (AUCD), the American Association on Intellectual and Developmental Disabilities (AAIDD),

and Self Advocates Becoming Empowered (SABE). Council Members and staff were joined by staff and members of the Arc of WV.

Partners in Policymaking (PIP): Christy reported that PIP is winding down. Three sessions have been held since the previous quarterly meeting. The February session was on Building Inclusive Communities, Person Centered Planning, Self Determination, and Social Roles. The March session focused on Education and Lou Brown was the main speaker. April's session was on Employment and Housing.

The final session will be held May 16-17. It will cover serving on boards and working with the media. Graduation ceremonies will also be held, and Esme Grant, the Public Policy Director for NACDD, will be the keynote speaker.

The next PIP class will begin in September, 2015. Some applications for that class have already been received.

Meeting with the State Dental Director: Linda thanked Ann for contacts she made that led to a meeting with Jason Roush, DDS, the State Dental Director, and Deonna Williams, the Oral Health Program Manager. Steve and Linda met with them on March 19th. The meeting was timely because the Oral Health Program is beginning to work on an update to the 2010 State Oral Health Plan. Dr. Roush agrees with the expansion of dental care for people with developmental disabilities through Medicaid, but acknowledged they do not have good data for convincing the State to do so. Jason mentioned DentaQuest in Boston and the Oral Health 2020 Initiative as possibilities for receiving some grant monies to study the dental needs of adults with developmental disabilities. Both Jason and Donna seemed eager to work on this issue and left with a promise to do some checking and to stay in touch with us.

Pat Nisbet reported that Dr. Roush also met with her and Kelly Johnson, who manages ICFs/IDD for the Bureau, to find out where people are. She reported they are negotiating with DentaQuest to do some surveillance.

Lou Brown presentation: Steve reported that Dr. Brown presented at PIP in March and that several Council Members, along with other interested parties, were in attendance. Dr. Brown is the leader in the field of inclusion and is now Professor Emeritus at the University of Wisconsin.

Meeting with RSA Commissioner: Steve reported that Janet LaBreck visited last month to learn more about the STEP and CTE projects through DRS and the Council. Both were originally DD Council grants. She met with people who got and kept jobs through these projects, and wants to see it replicated around the country. The Council hosted a lunch meeting with DRS, rehabilitation counselors, teachers, Beth Morrison, Karen Ruddle, Council staff, and Barbie Dallmann, Martha Minter, and Jeff McCroskey of Community Access, the grantee for these two projects. The Commissioner wants to bring her boss to see the projects and may offer funding for expansion.

Steve reported that he also met with the new Commissioner of AIDD, Aaron Bishop, who wanted to know more about these projects, the RSA, and what other innovative projects the WV DDC is involved with. It is possible that AIDD may also have money to offer for projects of this type.

Council Activity Book for Young Children: Steve advised Members that he sent the activity book to Members with children for their feedback because the Council recently received a couple of complaints about the book. Jonathan and Greg provided feedback. Overall, they felt the book was fine and still useful. Greg suggested an electronic version that children could access and complete on-line. Steve mentioned that one caller felt the book should include amputees since there are many coming back from war. Clarice added that the Administration on Intellectual and Developmental Disabilities has asked Protection and Advocacy programs to spend DD funding on veterans because many of them are young when they acquire a brain injury or have an amputation. More discussion by other Members followed.

Council Members' Comments and Concerns: None.

Completion of Meeting Evaluation Forms: Stacey asked Members to complete the evaluation forms before leaving.

Adjournment: Kelly moved and Greg seconded the motion to adjourn.
Motion carried.