

WV Developmental Disabilities Council  
Quarterly Meeting  
Holiday Inn & Suites, South Charleston, WV  
January 27, 2015

Minutes

**Members present:** Jonathan Chaffin, Joyce Church, Deborah Davis, Amber Hinkle, Janice Holland, Betty Holliday, Rickey Meade, Beth Morrison, Pat Moss, Pat Nisbet, Clark Queen, Jerry Ramsey, Tara Roush, Jon Sassi, Jenni Sutherland, and Tina Tanner

**Members absent:** Donna Ashworth, Greg Bilonick, Brent Bush, Stefanie Caldwell, Pat Elliott, Clarice Hausch, Ann Hubbs, Mary Etta Jones, Jane McCallister, Kelly Miller, Christina Mullins, Sheila Paitsel, Wanda Proffitt, Stacey Thomas, and Melvin West

**Staff present:** Christy Black, Jim Cremeans, and Steve Wiseman

**Guests:** Doug Auten, WV Division of Rehabilitation Services  
Susan Beck, Assistant Director, WV Department of Education, Office of Special Programs  
Pam Roush, Director, WV Birth to Three Program, Office of Maternal, Child and Family Health  
Jennifer Tenney, UCED, TBI/WIPA Program Manager  
Steve Brady, Jason Deussenberry, and Cassandra Tolliver, BBHMF I/DD Division

**Call to Order, Welcome:** Deborah Davis, Chair, called the meeting to order and welcomed all Members.

**Introductions and Announcements, Mission Statement Reminder:** Deborah invited everyone to introduce themselves. Following introductions, these announcements were made:

Steve Wiseman announced that a story featuring Tara Roush and her art and business will be published in an upcoming issue of Executive Magazine.

Pat Moss announced that the CED, WV DDC, Arc of WV and the Fair Shake Network will be getting together soon to shape a template that all of the organizations can use to disseminate and share policy alerts in a uniform manner.

Clark Queen read the Council's Mission Statement.

**Public Comment:** None

**Approval of October 28, 2014 Minutes:** Janice made a motion to accept the Minutes as written. Tara seconded the motion. **Motion passed.**

### **Other Business**

**State Plan and PPR Update:** Jim provided Members with an update on the status of the Council's two major federal reports: the Five Year State Plan and Annual Program Performance Report (APPR). He said that no substantive changes were made to Plan goals or objectives. A copy of the updated Plan goals and objectives were provided to the Members. The two reports were submitted to the Federal Administration on Intellectual and Developmental Disabilities (AIDD) on December 31, 2014. Jim said that the Plan is in its fourth year. A new five year plan must be submitted to the AIDD by August 15, 2016. He described some of the activities carried out by the Council to develop the current Plan (public forums, unmet needs surveys, etc). He will speak more about new state plan development at the April Council meeting. Jim said that the Council is completing or addressing about 60% of the objectives in the State Plan.

**Legislative Update:** Christy provided Members with the legislative update. She stated that over 200 bills were introduced in the Senate on the first day of the session. She shared a copy of the 2015 Legislative Statements with the Members. Christy said that she would be using the Statements to educate new members and new leadership concerning the Council's issues and priorities. Christy provided Members with a bill tracking list and information about the Governor's proposed budget.

Christy informed members that the ABLE (Achieving A Better Life Experience) Act passed in December. The ABLE Act will allow individuals and families of children with disabilities to save money for disability related expenses without losing Medicaid or SSI. Currently, the federal government and the WV Treasurer's Office are drafting new regulations. ABLE accounts will be classified as a 529 savings account. Christy will keep members up- to-date as she receives information.

**Grants Update:** Steve reported on the status of the Council's grants. Current grants (FFY 2015) started on October 1, 2014 and will end September 30, 2015. Steve said that Council is currently funding six grant projects, including a new school-based work exploration project. Last year the Council had \$56,000 *carry over* of funds not used in last year's grants. Steve projected that we may have \$45,000 leftover from the 2015 grants, which is less than 10 percent. Steve said that the Federal allocation to the Council has been reduced dramatically over the past ten years, and that we were going to have to be very conservative in funding future projects. He said that there may be some things that our Plan calls for that we cannot do if the strategy involves funding grants. This is primarily due to the sequestration which occurred a couple of years ago. Steve also discussed the grantee's match.

Steve stated that Linda has visits scheduled with grantees and will be conducting site reviews soon.

**Employment First Workgroup Update:** Jim provided an update on the Employment First workgroup. The group met on January 23 and discussed how to improve I/DD Waiver supported employment services. The group agreed that several new services and supports (listed in Report to Council notes) should be added to the I/DD Waiver manual, including customized employment methods (e.g. Employment Discovery process). Jim said that he will submit the Workgroup's recommendations to the Bureau of Medical Services, I/DD Waiver program by early February.

**Members' Issues and Concerns:** Joyce raised concerns about the changes made in the Non-Emergency Medical Transportation program. The program has a statewide vendor, MTM Management. Joyce said that people with disabilities must sign a paper now before they get on the bus that transports them to their day program. Some people with disabilities, like her brother, cannot speak or write. In the past, staff signed the necessary forms.

Tina said that she also has trouble with public transportation. She said she has to give two weeks notice of her travel needs.

Deborah raised an issue regarding participant directed goods and services provided through the I/DD Waiver program. She said that it has taken months to receive a

response from BMS regarding the status requests after an application is submitted (even when the budget has been approved). Deborah said the service is a lifeline for many families, and it is worrisome for them when a family member goes without goods or services that they critically need. Deborah said that she is also concerned about the dramatic cuts (75%) to the Family Support program.

Betty stated that it took about three months for her daughter to receive participant goods and services. She said she also relies on the Family Support program. Betty announced that she and her daughter have been providing volunteer services at the Good Samaritan Center in Fayetteville. She said that the Center is a faith-based program initiated by parents. Betty stated that the Center is a good example of communities working together. She added that the clothes and other items provided at the Center are in excellent condition; items that she or others who work at the Center would use.

Jon raised a concern about the lack of ABA (Applied Behavior Analysis) certified therapists in the State. Jon said that his grandson (who receives Birth to Three services) was recently evaluated by the Klingberg Center and his parents were advised to take his grandson out of West Virginia to get the services he needs. Jon said that staff at the Klingberg Center specifically mentioned New York, Ohio and New Jersey as states that could provide ABA services. Jon said that his grandson receives Medicaid which causes his family to jump through hoops to receive ABA therapy. John's family has to drive over an hour for his grandson to receive the therapy.

Pam Roush said that she has concerns about the advice provided by staff at the Klingberg Center. There are few qualified professionals (Board Certified Behavior Analyst/BCBA) who can provide ABA therapy in WV, and few have training to serve very young children. She said that the Birth to Three program formed a statewide autism leadership team (facilitated by Dr. Jennifer McFarland, Autism Training Center) that is studying BCBA personnel training. Pam said that there are some people who develop ABA therapy programs, but people who are certified are few and far between. Many people do not have insurance that covers ABA therapy, and if they do there are many hurdles.

Susan Beck (WV DE) raised a concern about a call she received from a parent who was looking for supports and services for her child who turned 21 years old. She said that the parent said that certain goods and services, such as tube feeding

supplies and diapers, are not covered under Medicaid once a child transitions to adult services. Deborah informed the Council about a form available to assist with this through APS Healthcare. Jenni stated that the ADRC's can assist with some of those services once a person transitions into adult services.

**Information Session on Education:** Susan Beck provided a summary of some of the changes made to WVDE Policy 2419 as well as the Department's current efforts to improve teacher training. She said that under the new policy, students with disabilities will be allowed to participate in regular graduation ceremonies. She also mentioned changes in how autism is identified based on new DSM -5 (Diagnostic and Statistical Manual of Mental Disorders) guidelines. This has raised concerns as parents may be required to obtain additional assessments to verify an autism diagnosis. Steve pointed out that although some students with I/DD will be able to participate in graduation ceremonies, they will not be counted in graduation statistics, and will leave school without a real diploma.

Susan said that she, Pat Homberg (Executive Director) and Ghaski Browning (Assistant Director) recently met with Steve, Christy, Michelle Norweck (Fair Shake Network), and Christina Smith (Arc of WV) about concerns raised in the Education Fact Sheet produced by the three advocacy organizations. Susan said that she and other staff from the Office of Special Programs share many of the concerns raised by the Council, especially the need for improved teacher training. Susan mentioned several summer training academies or "boot camps" including: Autism Academy led by Jim Harris (WV DE); PERC (Parent Educator Resource Center) Academy led by Betsy Peterson; and a Co-Teaching Academy.

Susan mentioned other Office of Special Programs initiatives including the State Systemic Improvement Plan that seeks to improve graduation rates and post high school outcomes. One initiative is a collaborate effort of the WVDE, Marshall, Concord and West Virginia Universities to better prepare general education teachers to teach students with IEPs in their classrooms. Susan said that a \$9.7 million SAMHSA (Substance Abuse and Mental Health Services Administration) grant titled Project AWARE will address mental health needs of students and support for parents and caregivers. Susan said that the Autism Training Center at MU received a portion of the funds to increase outreach to students with autism and their families.

Steve asked about the status of enrollment in Career Technical Education (CTE) programs by students with severe developmental disabilities. Susan did not have specific data but said the Individualized Work Readiness Certificate (IWRC) program continues to be available in several counties. Steve stated that the IWRC program was the result of a Council funded demonstration project with Vocational Services, Inc. and that the Council was very concerned about seeing the program expand throughout the State.

Jonathan Chaffin stated the when he talks to other parents, what he hears is that you cannot get past the school administrators. He said that one administrator said that "I don't want those kids in my school." Jonathon asked Susan how parents should respond to such comments and opinions before they have to go through due process. Susan said that she is hopeful that the new facilitated IEP process will help. Susan said that some WVOSP staff traveled to Oregon to learn more about facilitated IEPs, a process in which a knowledgeable and independent person directs meetings and IEP development. Susan also mentioned that the WVDE has instituted an A-F grading system for schools. In order to obtain a good grade, schools must show that the bottom 25% of student performers have improved to high growth status. Janice asked if there were fiscal resources attached to the endeavor. Susan stated that she didn't know but schools that have poor scores will get support.

**Information Session on Work Incentive Planning & Assistance:** Jennifer Tenney, UCED Program Manager of WIPA/TBI discussed the Work Incentive Planning and Assistance program. Jennifer stated that in addition to her, there were just four certified benefits counselors in the state. Jennifer said that people with I/DD who receive Social Security benefits can work in the community and retain health and cash benefits. She said that although work incentive rules can be complicated, everyone should understand that people who receive SSI are always better off when they work. Jennifer said that people on the I/DD Waiver can earn up to 300% of the SSI rate and keep the Waiver benefit.

Jennifer said that there are two major programs (SSI and SSDI) and two separate sets of rules. She said that having a job does not have to affect eligibility for benefits. It was stated that Medicaid insurance was easier to protect than food stamps or HUD housing subsidies. She suggested that people should contact the certified benefits counselors at WIPA to learn more.

**I/DD Waiver Update:** Pat Nisbet, Bureau for Medical Services, provided an update on WV's Transition Plan to comply with the new final Federal rule for CMS Home and Community Based Services requirements. She said that a framework and transition plan will be submitted to CMS by February 1, 2015.

**Update on Family Support and other DD Division Programs:** Beth Morrison, Steve Brady, Jason Deussenberry and Cassandra Tolliver provided updates on programs and services that support families and people with I/DD. Steve B. said that the Division has funded six (6) **Customized Employment projects** across the State. Steve B. mentioned several success stories from the employment grant programs. He said that some changes were made to the **Unmet Needs** funding process including the requirement for more financial information from applicants. He said that several people who requested funds had reached their \$2000 asset limit with Social Security, and that they receive counseling about spending down funds. Steve B. said that the **I/DD Waiver Support Grant** program continues to serve more people (5 in 2010 and over 50 going into 2015). Some funds were supporting staff who are providing facility based day habilitation services. Janice H. asked what is happening to transition people out of workshops in light of new CMS rules. She asked about what the DD Division planned in terms of training personnel about helping people get real jobs. Beth said that those were important issues that the Division and others will be addressing in the future. Janice said that any plans need to address financial incentives (and disincentives) around community employment outcomes for people.

Jason said that a total of \$850,000 has been allocated to agencies in six (6) regions of the State. Those funds were provided to assist people with chronic mental illness stay out of psychiatric facilities and for families of people with I/DD. Questions were raised about how funds will be prioritized for the families of people with I/DD. Deborah asked what would happen if a family comes to a grantee and is told that their loved one's needs are not severe enough for funding. Jason said that a situation like that described by Deborah has not come up. Cassandra said that regional Family Support Councils are made up of parents who understand the needs of families with sons or daughters with I/DD. Jason said that the Regional Family Support Councils have primary decision making authority concerning use of funds, not the BHHF.

**Adjournment:** The meeting was adjourned by acclamation.