

WV Developmental Disabilities Council
Quarterly Meeting
October 22, 2019
Mountaineer Conference Center, Beckley, WV

MINUTES

Members present: Kenneth Accord, Doug Auten, Brandy Beery, Rhonda Blosser, Steve Brady, Cali Brill, Janie Cole, Julie Dial, Marc Ellison, Dawn Embrey-King, Tonya Eve, Lynsay Frye, James Gallaher, JaQue Galloway, Sherill Hoffmann, Susan Loudermilk, Kristin O'Neal, Jacqueline Proctor, Pam Roush, Tara Roush, Jon Sassi, Rebecca Stone, and Sheila Zickefoose.

Members absent: Patty Combs, Lesley Cottrell, Delmar Davis, Nora Dillard, Susan Given, Richard Hammons, Wanda Proffitt, and Matthew Wink.

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

Guests: Angela Akers (The Un-Prescription Foundation for Autism Inc.), Taniua Hardy (DRWV), Randy Hill (BMS), Emily Hopta (DHHR), Amber Moore (BCF)

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

Introductions and Announcements: Kristin invited everyone to introduce themselves and welcomed new Members Janie Cole and Sherill Hoffmann. She called Members' attention to the notice in their packets of next year's meeting dates and locations. They are as follows:

January 28 – Four Points by Sheraton, Charleston

April 28 – Holiday Inn-University Area, Morgantown

July 28 – Summersville Arena & Conference Center, Summersville

October 27 – Blennerhassett Hotel, Parkersburg

Rebecca announced that deadline for the first award from the Luke Stone Illumination Fund is October 31st.

Mission Statement Reminder: JaQue read the Council's Mission statement.

Public Comments: None

Approval of July 23, 2019 meeting Minutes: Tara made a motion to approve the Minutes as written and Sheila seconded the motion. Motion carried.

New Business

Budget Update/Call for Investments: Steve reviewed with Members the change in interpretation from the Administration on Community Living on how Councils can allocate and spend funds. FFY2017 funds expired on September 30, 2019. FFY2018 funds will expire on September 30, 2020, and FFY 2019 funds will expire on September 30, 2021. FFY 2020 funds will also expire on September 30, 2021. Beginning with FFY 2020 DD Councils will have only 24 months to obligate and spend their annual allotments. This change will result in the loss of a full year's use of future allotments.

He reminded Members the Council added four new grants which are anticipated to be funded for three years each.

He also updated them on the hiring of staff in the office. Christy recently was transferred to the State employee Advocacy Specialist position, interviews are currently being conducted to fill the Administrative Assistant position, and he plans to advertise the Planner's position soon.

He advised Members the Council will begin the process of developing the new State Plan (2022-2026) in the next few months. Members will be actively involved in the process.

Steve proposed the Council revisit an old proposal to fund a "State of the State" report for up to \$90,000 in preparation for the new State Plan. **Jon moved** and **Sheila seconded** the motion to spend up to \$90,000 for a vendor to do a comprehensive review and analysis of State policies and systems (not to include school services) to determine the status of community supports for people with developmental disabilities, and to make recommendations. **Motion carried.**

Elaboration on key legislative issues:

I/DD Waiver wait list – Steve and Christy met with a State Senator and key DHHR personnel, along with other advocates, to discuss the wait list. \$19 million was suggested as the amount needed to clear the wait list. It is realized there are other issues that will need to be addressed, including the problem with hiring and retaining adequate staff to support people.

Supported Decision Making – Steve and Linda participate on the WV Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) group. The

Council is also working with Disability Rights of WV to look at model legislation which might be able to be introduced in WV.

Employment First – the intent of having an Employment First initiative is to rule out integrated employment before choosing other options for what to do during the day. Over 30 states are already Employment First states. The WV Legislature introduced a bill to establish West Virginia as an Employment First state last year but included a section on the elimination of sub-minimum wage for people with disabilities, which caused the bill to die.

Advance Directive Bill – West Virginians for Life reached out to the Council to discuss a bill regarding informed consent on the Living Will document after some of their members attended a workshop the Council sponsored titled First Do No Harm. This bill would add two boxes for a person to check indicating their wishes on whether or not they want food and/or fluids, by mouth or by gastrostomy tube. Linda discussed the growing movement of Physicians Assisted Suicide (PAS) and how people with disabilities are vulnerable.

Executive Committee/Legislative Workgroup – Legislative Statements: The Executive Committee reviewed and proposed changes to the Council’s Legislative Statements. A draft is included in Members’ packets. **Brandy moved** and **Lynsay seconded** the motion to approve the Legislative Statements as written. **Motion carried.**

Executive Director’s Update: Steve informed Members that Linda recently spoke about the inequality in medical care and the dangers of physician assisted suicide for people with developmental disabilities at a Palliative Care Conference in Bridgeport. Steve was the keynote speaker at the Arc of the Mid-Ohio Valley’s 64th Annual Meeting/Dinner. His topic was, “The Key to Community is You” in which he stressed the need for individual initiative and a focus on community building.

He reminded Members the new grant with the City of St. Albans has begun. The intent is to demonstrate people with developmental disabilities being included in making improvements to their community. Having freely given, meaningful relationships with others in the community increases safety and decreases the chances of having bad things happen to you.

He told Members he was able to get the two State positions back that were swept in January, the Advocacy Specialist and the Administrative Assistant, and will also be filling the position of Planner soon.

Steve informed Members the Council will hire a consultant, as usual, to assist with the State Plan process.

Per the recommendation of the Partners in Policymaking Workgroup, the “PIP” training seminar is being broadcast over the internet to allow people who live more than 100 miles from Charleston to participate more easily. The Council will be getting a new phone system in December which will involve a change in phone numbers. The website is being re-designed to have a new, less cluttered, look.

Presentation – Integrated Employment: A Pathway to Success: Kristin presented information on how to obtain integrated employment using her experiences with her daughter. Kristin stressed the need for high expectations, the use of the “discovery” method, the attainment of valued social roles, and relationships as keys to success. A copy of the presentation was provided in Members’ folders.

Presentation – Sensory Kits – Angela Akers, Director of The Un-Prescription Foundation for Autism Inc.: Ms. Akers showed Members a sensory kit she has developed which can be used in emergencies or other situations in which people need ways in which to calm themselves. It includes headphones, sunglasses, and a sensory brush – items that are helpful to people with different sensory needs.

Presentation – What WVDE is Doing & Focusing on for Students with significant Cognitive Disabilities – Dawn Embrey-King, Deputy Director of Office of Special Education: Dawn provided updates on how students with significant cognitive disabilities are being educated. She presented on the appropriate identification of students who should be on the alternate standards and assessment, for which the state now has a cap of one percent of students. Dawn discussed that as a means of the state being aligned with the *Every Students Success Act* (ESSA), the Alternate Diploma replaced the Modified Diploma. West Virginia is one in only a few states that have done this. The alternate track curriculum is standards-based, unlike the previous function-based approach, and the standards are aligned with the WV College and Career Readiness Standards. Dawn went over a case study so Council members could understand how the decision is made concerning which track a student would follow. She stressed that achieving a “personalized education plan” for every student was not easy, but it is possible. She discussed the universal design possibilities to reach all students.

Council members raised some questions/issues about the preparation of general education teachers to teach students with severe learning impairments; what

schools are doing to address the disparity of African American students in behavior disorder related classes versus those for students on the autism spectrum; and concerns about disparities of African American students in the areas of diagnosis, discipline, and the “pipeline to prison.”

Dawn stated the county school districts were aware of the disparities regarding minority students. The Department of Education is committed to positive behavior support and has embedded it in the standards and the technical assistance to the counties.

Discussion – Minority Disparity in Services and Diagnosis Specific to Autism –

Marc Ellison: Marc provided Members some information related to the Council’s State Plan goal in addressing the disparity in students of minority status being over-diagnosed with behavior disorders and under-diagnosed with autism. This is not just an issue in West Virginia; it also occurs nationally.

In general, he reported the average age of diagnosis is now four years, four months. This is earlier from the previous average age of six, but still causes many children to miss out on appropriate early intervention services. A prevalence study (CDC, 2017) showed that 1.3 million children have been diagnosed with autism.

African American and Latino children are generally diagnosed about two years later than Caucasian children. The prevalence gaps do not close based on socio-economic status.

He reported West Virginia has few diagnostic centers. There is a multi-disciplinary diagnostic team at the Klingberg Center in Morgantown, and a part-time team at Marshall University.

Autism Training Center at Marshall University is doing outreach with pediatricians on how they get children ages two-to-four with obvious signs diagnosed quicker. Marc also stated that sensory issues related to the effects of opioid use by parents can be confused with those associated with the autism spectrum disorder.

Adjourn: Kristin reminded everyone to complete the meeting feedback forms. **Tara moved** and **Doug seconded** the motion to adjourn. **Motion carried.**