

West Virginia Developmental Disabilities Council
Quarterly Meeting
Country Inn & Suites, Beckley, WV
April 27, 2010

Members Present: Christy Black, Bob Cain, Joyce Church, Richard Covert, Ron Dean, Jeannie Elkins, Sandy Haberbosch, Clarice Hausch, Amber Hinkle, Betty Holliday, Stephanie Jackson, Carlos Lucero, M.D., Clint Martin, Jane McCallister, Pat Nisbet, Richard Perry, Clark Queen, Jerry Ramsey, Karen Robinson, and LuAnn Summers.

Members Absent: Virginia Gattlieb, Janice Holland, Ann Hubbs, Julie McClanahan, Pat Moss, Libby Nester, Karen Ruddle, John David Smith, Tina Tanner, and Pat Winston.

Guests: Randy Hill, APS.

Staff Present: Steve Wiseman, Jim Cremeans, Linda Higgs, and Tiffany Wiseman.

Staff Absent: None.

Welcome, Introductions, and Announcements

Jeannie called the meeting to order and welcomed all Members. All Council Members introduced themselves. Jeannie welcomed Pat Nisbet, who will now represent the Bureau for Medical Services (State Medicaid Agency).

Mission Statement Reminder

LuAnn read the Council's Mission Statement.

Public Comments

None.

Approval of January 26, 2010 Meeting Minutes

Jeannie asked Members to review the January 2010 Council Meeting Minutes to determine if any corrections need to be made.

Ron moved the Minutes be approved as presented. Christy seconded. Motion carried.

New Business

Five Year Plan

Jim reviewed the Five Year State Plan goals. He explained a survey will be developed and disseminated to determine areas of emphasis for the next Five Year State Plan. Public forums and other methods will be used, as well, to collect information to aid the Council in determining the areas of emphasis and setting Goals. The Plan will be submitted by August 2011. Jim also gave an overview of several areas the Council must focus on in the future to develop the Plan.

LuAnn asked if Council staff intend to complete forums as it was in the past. Jim stated staff intends to use the same forum “café” process used during the last forums. Several small stations were offered in the forums to discuss particular topics like employment, healthcare, education, transportation, quality assurance, etc. LuAnn stated that she felt the method was informative and very beneficial. Clarice said the information obtained was also useful to the WV Advocates. She also indicated a meeting took place after the forums that she would like to see taken further. The Council identified areas needing to be addressed outside of the scope of Council funding and abilities.

Jim asked that anyone wanting to be on the State Plan Workgroup to contact him.

Election of Executive Committee Members

Jeannie informed the Council Jerry Ramsey, Richard Covert, Betty Holliday, Ginny Gattlieb, and Pat Moss volunteered to be on the ballot for the Executive Committee election. Council Members voted by ballots for three individuals from the slate for the new Executive Committee.

Richard Covert, Pat Moss, and Jerry Ramsey were elected to be on the Executive Committee. They join Jeannie, Bob, and Christy.

Call for Investments Allotment

Steve reviewed current Council grants and the amounts awarded to them. Several projects were awarded higher amounts than typical. He also shared which projects he expects to reapply for Council grant funding this year. Steve used this information to project the amount of funding available for the next fiscal year.

Steve explained the Council will not see an increase in federal funding. The amount of funding may remain flat for the next three years. For this reason, it was recommended the Council not solicit new grant proposals. However, the Council

could fund still fund projects and partner with other groups. Jeannie stated the Executive Committee discussed this idea last night and agrees it should be considered. The Executive Committee and staff also discussed the possibility of promoting current projects or getting some incomplete Council projects off the ground.

Clarice stated she is very happy to hear the Council has responsibly spent money. With the authorization of several Acts coming up, including the DD Act, it sends a bad message to Congress if all funding is not used to support those individuals the Acts were created to support.

Steve recommends no action at this time. LuAnn asked what money is projected to be available if the Council does not advertise for grant projects. Steve projected about half of the usual amount will be available.

Joyce stated people have come to expect the Council to advertise grant funding availability. She asked if the Council can still fund projects if people apply for them. Steve stated that this would be difficult due to purchasing rules.

Jeannie stated action is needed.

Christy made a motion to not go forward with a CFI announcement. Clint seconded. Motion passed.

Designated Stipends Allotment

The Executive Committee discussed the Designated Stipends Allotment for fiscal year 2011. The Committee recommended the Council fund the same amount as in FY 2010: \$32,000.

Karen Robinson made a motion to accept \$32, 000 for the Designated Stipends Allotment. Ron seconded. Motion passed.

Legislative Wrap-Up

Regarding Federal Legislation:

Clark explained Steve and he visited staff of Representatives Rahall, Capito, and Mollohan. Sarah Brown and Christina Smith, who both represented the ArcWV and People First of WV, visited the Senators' offices. Clark and Steve discussed several issues with the Representatives including the seclusion and restraints in schools bill, housing for people disabilities, and the long-term care pieces of the recently passed healthcare reform.

Also included in that legislation was an increase in Medicaid funding rates to all States. Steve discussed this in relation to the Social Security Section 1915 I Medicaid option that had been passed a few years ago but had not been implemented by states. It provided for a greater federal share for expenses to support people to live in the community rather than institutional facilities. The regulations including eligibility, etc. are seen by states as in conflict with other Medicaid programs.

Karen Robinson asked where WV stands on this issue. He stated that while no state has accessed that Medicaid option to this point, he does not know the thinking of the DHHR/BMS on this currently. Pat Nisbet said she will be attending a conference concerning this option and would report back to the Council.

Steve reported the Federal administration had ‘zeroed out’ the supported employment line item of the Federal budget. Those funds (or part of them) would be moved to a more general rehabilitation budget line item that states could use for needs they determine they have. A new line item for grants regarding the employment of youth was created.

While on Capitol Hill, Clark discussed his job as well as the need to eliminate barriers to obtaining meaningful, paid employment for people with developmental and other disabilities.

Steve also discussed the ABLE Act that would set up a government based trust. It is a little different from a Special Needs Trust.

Regarding State Legislation:

Steve discussed the bill to change the language in WV State Code from “mental retardation” to “intellectual disability.” It was initiated by the Arc of WV and People First. The bill passed but was vetoed by Governor Manchin due to technical issues.

The Community Services Act was another State bill followed by the Council. It involved the redirection of funding from nursing homes and other institutional settings to help individuals live at home and in the community.

A bill of particular interest to the Council was one concerning the law governing authorized medication administration personnel. The bill would permit individuals to receive medications from their staff persons when the individuals are in the community. The bill included three other provisions related to medication

administration. The bill did not pass. However, as a result of the discussions on this issue, the Office of Health Facility Licensing did change its policy to allow medications to be passed to individuals by those trained and authorized when the individuals are in the community.

The Ron Yost and other Division of Rehabilitation Services (DRS) programs did not receive additional funding. DRS has been using Federal Recovery funding to cover the lost funding for those programs. The legislature made \$7.5 million available to the MR/DD Waiver program. Karen Robinson asked if the funding will cover the 150 slots to be added to the MR/DD Waiver. Randy said that it will cover those slots. Steve said many (emphasis added) people beyond the 150 could be supported with that amount of match funding.

Karen Robinson asked if individuals who qualify for more than one Waiver program (MR/DD and Aged and Disabled) could choose the program they apply for. A TBI Waiver is currently being proposed in WV. Randy said that individuals can choose the program which most closely meets their needs. Clarice stated that each program offers different types and amounts of services, which should be considered when choosing a program. The TBI Waiver is still in the planning stages. Karen stated five people were at the TBI Waiver forum she attended. Under the proposed criteria, none of the individuals would qualify. Clarice stated that in the proposed application, an individual must currently be institutionalized to be eligible for the program. Karen stated that during the forum, attendees were asked what services they currently receive and their wish list of services.

Betty asked how the five percent State budget cut will affect the MR/DD Waiver program. Randy stated the Governor, in anticipation of the projected State budget shortfall, has asked all State agencies to review their budgets to determine where cuts can be made. It is not mandatory at this time.

Steve shared that the \$7.5 million amount passed by the Legislature for the Aged and Disabled Waiver was reduced by the Governor to \$2.5 million. The Governor initially reduced the MR/DD Waiver increase. It was later restored to the full amount.

Karen stated she was told all Waivers were started with meager funding and services. She questioned if it is harder to change the program later. Randy stated the development of Waivers has changed from the 1980's.

Council Member Terms

Jeannie explained half of the Council Member terms will expire in 2012. The Executive Committee has discussed this issue and feels they have determined a way to avoid this problem. The Committee proposes the two vacancies that have two years remaining on their terms be replaced with four year terms. In 2012, we will make three terms be for two years, and five terms be for four years. This will then allow the Council to have five expiring terms each year thereafter.

Joyce made a motion for the Council to fill the two vacancies with four year rather than two year terms. In 2012 we make three terms be for two years, and five terms be for four years. Sandy seconded. Motion passed.

Committee/Workgroup Reports

Nominating Committee

The Committee met on April 6 and reviewed all the applications received. Applications were considered based on several criteria, including: type of developmental disability, geographic location, race/ethnicity, and current Council composition.

The Committee chose two applicants for Council approval:

- Sarah Brown – an individual with a developmental disability from Harrison County, and
- Kelly Miller – the parent of an 11 year old daughter with Down's syndrome from Lincoln County.

Sarah was recently elected Chair of the State People First group. Kelly is in the current class of Partners in Policymaking.

Jerry made a motion for the Council to submit applications from Kelly Miller and Sarah Brown to the Governor for appointment to the Council. Joyce seconded the motion. Motion passed.

Other Business

Members' Issues and Concerns

Carlos expressed a concern about the recent mining tragedy. He also wanted to express concerns about the environment and our responsibility to preserve it for the generations to come. He would like to see the U.S. reduce its dependency on carbon fuels. He encouraged Council Members to contact legislators about their environmental concerns.

Jeannie stated the issue of environmental toxins is addressed in the Council Priorities publication.

Clark expressed his gratitude for having the opportunity to attend the Disability Policy Conference in Washington D.C. and meet with WV's congressmen.

Karen asked if the *Start to Finish* (IEP related) training will be held Thursday, April 29, 2010. This event is sponsored by the Fair Shake Network. Tiffany stated to the best of our knowledge, the training will be held. An incomplete flyer was emailed. Then, an updated flyer was sent out. Jim said he would check on Karen's registration.

Linda notified Council Members that Wills and Special Needs Trusts workshops will be offered by the Council in Parkersburg and Lewisburg. The registration deadline is coming up soon. If there are not enough registrations, the trainings will be canceled. She asked all to send in their registrations and/or share the information with others.

Other Business

MR/DD Waiver Updates

Randy stated he reviewed the January 26, 2010 Council Meeting Minutes to determine the areas of highest importance. He also reviewed the role APS will have in the WV MR/DD Waiver. He briefly discussed the APS forum held in the spring and notified Members that more forums will be held after the Waiver application has been approved. Participants and families on the MR/DD Waiver program will be invited to the forums to gain an understanding of changes to the program.

Randy gave an overview of the proposed changes to the MR/DD Waiver program. To make information more readily available, participants and families will be able to access their information and updates through an online system like their Service Coordinators can do. Other changes included:

- Waiver application submission on June 1, 2010 rather than April 1, 2010;
- elimination of annual nursing assessment requirement;
- simplified documentation for direct care services;
- physician DD-2 codes;
- elimination of high school diploma/GED requirement for direct care staff;

- clearer guidelines regarding caps on services;
- elimination of active habilitation requirement;
- new “Person-Centered Support” service that consolidates existing Residential Habilitation, Community Day Habilitation & Adult Companion services (perhaps hour unit instead of 15 minutes unit);
- more flexible options of providing oversight for participants’ health and safety;
- elimination of annual diagnostic assessment requirement;
- elimination of mandatory day habilitation;
- eligibility of 8 hours of nursing services per day, 365 days per year (yearly cap rather than a daily or monthly cap)
- “streamlined eligibility process”;
- shortened medical necessity form;
- elimination of social history code;
- elimination of social worker IPP code;
- maintaining a Community Residential Habilitation service under the traditional service model; and
- option for participant directed services.

Randy gave an explanation of the Participant-Directed Services Option (PDSO). He stated PDSO is a person-centered service delivery system where individuals have greater choice and control over the services they receive and the individuals who provide them.

Pat stated an attempt was made to change the name of the Waiver from Title XIX MR/DD Waiver to ID/DD (Intellectual Disability/Developmental Disability) Waiver. It was denied by CMS. However, if enough public comment is received to change the name of the Waiver, CMS will consider it.

Steve expressed his concern about video monitoring and surveillance being a billable service for Behavioral Health Provider agencies. The technology could be misused and abused. He also asked if some lower technologies could be accessed through Goods and Services (e.g. walkie talkie). MR/DD Waiver participants could gain some independence through the use of some technologies.

Joyce stated her fear that people (staff) will be replaced with technology. She stated this type of technology was not helpful to her father, who fell out of his bed at a hospital, despite video technology. Additionally, individuals with disabilities will lack interaction.

Sandy stated this type of service would be an invasion of privacy. Jeannie, like Joyce, felt there is a possibility that agencies will use the technology when staff is not available/hard to find.

Amber stated this type of technology could be quite liberating to those who do not 24 hour staff, especially at night. Some people do not want someone at their home, watching them sleep. The opportunity could be freeing.

Pat Nisbet stated this technology would not be placed in private areas (e.g. bathroom and bedroom). It would be placed in common areas like the kitchen or living room.

Randy expressed the proposed Waiver changes are considered in order to provide more options and a more individualized program. For instance, "Goods and Services" will be available through the PDSO. Unlike Environmental Accessibility and Accommodations, Goods and Services can allow the purchase of a gym membership in improve health and fitness. Goods and Services goes beyond environmental modifications to increase accessibility.

Also available through PDSO, is negotiable caps on services like transportation, person centered support service, etc. However, the change in caps must be justified. Flexibility in staff wage is also available.

Randy gave a brief explanation between the difference in "Agency with Choice" option and PDSO. Under Agency with Choice, responsibility to hire, fire, train, and support staff is shared between the participant and the agency. The participant will have more choice and control than in a traditional Waiver program.

Under PDSO, the participant will receive training as to how to hire, fire, and train staff. The participant will have more choice and control than in the traditional Waiver program or the Agency with Choice option. However, the participant retains ultimate responsibility.

Randy explained when PDSO will be available. First, a training and application period will begin July 1 (as long as all timelines are on time) and end October 1. The earliest anyone will be able to sign up to direct their own services is October 1, 2010. A transition plan must be completed for everyone who signs up to direct their services.

CMS is currently assessing how individuals eligible to the open slots on July 1, 2010 will be able to fill those slots. The change to person directed Waiver services on October 1 could cause confusion. CMS is currently discussing how to address this issue.

Clarice asked how the elimination of the initial psychologist diagnosis determination would affect individuals with strictly physical disabilities that make them eligible for services.

Amber expressed her concern that the same group training psychologists to complete eligibility evaluations will have final say over eligibility. It appears to be a conflict of interest. So much money has been used through the appeals process and it appears recommendations have been ignored. Clarice agreed. She stated the Court system has determined that people with Asperger's cannot be denied services based on that diagnosis. Yet, the DHHR contracted psychologists have continuously denied or terminated services to individuals because of their diagnosis. Randy stated he feels the changes proposed should lower or eliminate these issues. The new Network of Psychologists should lower mistakes like the use of the wrong test to determine an individual's eligibility.

Christy agreed with Clarice. Through her experience there has been a conflict of interest. She hopes to see a change to the MR/DD Waiver to remove this conflict of interest.

Feedback Forms

Jeannie requested all present to complete and turn in the Meeting Feedback Forms.

Adjournment: By acclamation.

Next Meeting: July 13, 2010, Charleston Civic Center.