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WV Developmental Disabilities Council
Comments on
Chapter 513 (IDDW Manual) Draft (revised (10/1/2015))

We realize that CMS has approved the Application for the new Waiver, but the Council still has serious concerns about the cuts being made to this program and its effects on individuals with developmental disabilities and their families. We also have comments on apparent new policy to be implemented through this draft Manual. They are generally listed in the order in which they appear in the posted document.

For the past few years, the Council has had a Workgroup on issues related to the lack of employment of people with developmental disabilities. Some of those Members and Council staff participated in a workgroup of the Quality Improvement Advisory (QIA) Council to the Bureau for Medical Services, where many suggestions for additions to the Waiver program were offered. It is disappointing to see that very few of those suggestions have been included in this Manual.

While Pre-Vocational services were added to the program, **513.3.9 Pre-Vocational Agency Staff Qualifications (p 23)** indicates that no new qualifications for staff are being required. There are numerous potential benefits to pre-vocational services for individuals with developmental disabilities, and the various components of this require knowledgeable staff to carry them out.

Likewise, there are no new, relevant requirements in **513.3.5 Job Development Agency Staff Qualifications (p 22)** or **513.3.16 Supported Employment Agency Staff Qualifications (p 25)**. Later in the Manual, there are allusions to extra qualifications needed for these two.

The section **513.8 Individual Program Plan (IPP) (p 37)** now states, “The person who receives services must attend the IPP.” This is a change in policy. The current Manual requires the member to attend if they are their own legal representative, and if they are medically and behaviorally able. There must be a means of making rare exceptions for the well-being of some people.

Section **513.8.1 The Interdisciplinary Team (IDT) (p 39)** now lists an “order of importance” in which services must be prioritized and purchased: “Person-Centered Supports, Facility-Based Day Habilitation, Pre-Vocational, Job Development, Supported Employment, Electronic Monitoring, LPN services, and Respite Services.” What are the implications? Does the State value Facility-Based Day services or Electronic Monitoring, for example, over Respite services? How will this affect access to Respite services – an ESSENTIAL service to the person and his/her family caregivers?

513.9.2 Participant-Directed Service Option (p 48), No. 11, requires the Personal Options FMS to explain all costs/fees associated with participant-directing to the person who receives services. What are the costs/fees? They do not appear to be listed in this Manual.

While the Council remains generally opposed to the use of 513.13 Electronic Monitoring (p 61), it needs to be pointed out that these hours are in combination with all other hours of service. Therefore, if agencies and/or families bill the maximum allowable (12 or 8 hrs/day) of needed services, this service will not be available to them.

It seems extreme to require people to include the “specific item requested” under **513.14 Environmental Accessibility Adaptations (pp 61-62)** in the IPP. Since IPPs must be developed early for the year, an individual may know they will be looking for a home or vehicle adaptation but may not know the “specific” adaptation that will be available to meet their needs. Acknowledging the need and intent so that monies can be budgeted should suffice. To hold additional meetings to amend the IPP for this purpose adds unnecessary cost and inconvenience. The “specific” adaptation must be approved by the UMC prior to purchase anyway.

The Council wholeheartedly supports the new Federal Home and Community Based Services (HCBS) integration rule which is causing the State to transition from **513.15.1 Facility-Based Day Habilitation (pp 63-65)**, but it must be acknowledged that not all people will be able to transfer to more employment related services (pre-vocational, job development, or supported employment). Yet, unless they access those services they will only be able to access 8 hours of services per day. Those who can access those services will have 12 hours of services per day available to them. There needs to be a means of increasing the hours of person-centered support services for those who will no longer have another service available to them. People with the most severe levels of

impairment and those who have attended segregated services for many years are at the greatest need in this regard.

A few such people may be able to transition from day habilitation to pre-vocational services since it appears they will be offered in the same day program facilities. Still, this service is time limited to two years.

Since **513.15.2 Pre-Vocational (pp65-66)** services will be offered in the same settings as Facility-Based Day Habilitation, and since they can potentially be offered concurrently (some people may wish to access this service now, rather than wait three years), how will this be accomplished? Will there be a division of space and staff? Currently, it is often very hard to tell if those served in day habilitation settings have individualized goals. Will it be possible to distinguish the difference between the two services, and from individual to individual?

It is stated that **513.15.3 Job Development (pp 67-68)** services can also be offered in a Facility-Based Day Habilitation setting, so the same questions as above apply. More importantly, how can true job development be provided in such a setting?

It is encouraging to see documented training or experience in the implementation of Supported Employment plans of instruction will be required for those staff providing job development services and/or **513.15.4 Supported Employment (p 70)** services, although there is no mention of what this training entails, from whence it comes, or by whom it will be provided. In **513.3.5** and **513.3.16** of this Manual, specific information regarding acceptable training should be stated as it is for other services. It is also unclear as to what knowledge and skills agency appointed Supported Employment Services supervisors or Behavior Support Professionals would have related to job development or supported employment services.

The exclusion list for **513.16 Goods and Services (pp 72-73)** in the Application is much longer than the list in the Manual. Which is it? Still, the list is long. It might have been easier to make a list of what could be covered. Clothing is excluded, but some individuals may need adapted clothing that is “related to their qualifying disability.” The costs for “specialized” clothing, etc., can be much greater than comparable clothing that is not adaptive.

The Application specifically excludes computers and communication devices for anyone under the age of 21 and allows only when prescribed by a

speech therapist for those over 21. Language development and acquisition, and/or an alternate means of communicating is particularly important for children. Both items can meet the test of “promoting full community inclusion” and possibly “increasing a person’s safety in the home environment.”

When this service was first added as an option an example given was a gym membership for both the health and social integration/relationship building opportunities it could provide. Why then, would summer camp be excluded for children, especially if the camp is inclusive? Again, this is an example from the Application not listed in the Manual.

Limitations/Caps for **513.17.1 Family Person-Centered Support (pp 73-78)** indicate that the amount of service is limited by the individualized budget of the individual, however, we regularly hear from families that they have been assigned a budget that they cannot access due to the caps on services (particularly for children).

Although the Application with the drastic restriction in hours (particularly for children) was approved by CMS, the Council continues to disagree with this cap in services. The Application originally allowed for 4 hours of services on school days and 6 hours of services on non-school days. Changing the allowable services to 5 hours of services is not an increase. Rather, it is the average of the original plan.

The Council disagrees with the blanket exclusion of PCS Family services provided by natural family members for hospitalized individuals “when behavioral needs of the person who receives services arise due to the temporary to change in environment.” This should be available as it is for persons who reside in other settings.

The limitation not allowing the equivalent monetary value of Respite Services to be converted to needed **513.17.1.2 Family Person-Centered Support (Personal Options Model) (pp76-77)** services does not fit with the participant-directed model of services. True participant direction allows participants to spend their budget on services as they see fit. Since the rates for both services are the same, it does not appear to be a cost saving matter.

The cuts in PCS and Respite Services have caused many family members to tell us they will be unable to remain employed. Already, in planning forums the Council has been holding across the State, we have heard families who are

employed outside the home express their concerns for their jobs. One State employee relayed to us that, upon informing his supervisor that he would need to cut back on traveling since he is a single parent who supports his son, he was told that he would need to “figure it out” since that was his job. If State agencies do not understand the conundrum faced by families there is no reason to think private employers will be more sympathetic.

As the Council stated in comments on the Application, for those who have already given up work outside the home in order to care for a family member, this constitutes a cut in income that has helped them to support their families. We continue to believe these cuts will potentially have negative impacts throughout the systems in the state that are designed to support those with low incomes – Medicaid, TANF, SNAP, and other services.

Here again, the Council disagrees with the blanket exclusion of PCS Family services by natural family members for hospitalized individuals “when behavioral needs of the person who receives services arise due to the temporary to change in environment.” This should be available as it is for persons who reside in other settings.

And once more, the Council disagrees with the limitation on services in **513.17.2 Home-Based Agency Person-Centered Support (Traditional Option) (pp 78-80)** for hospitalized individuals “when behavioral needs of the person who receives services arise due to the temporary to change in environment” to be available for people who live in Specialized Family Care Homes, Unlicensed Residential Homes, and Licensed Group Homes, but not to natural family members. The needs of the individual are not different based on their residence in this regard.

The Council is also concerned that the reduction of PCS for children to 5 hours/day may make it impossible to find staff that is willing to take a reduction in work hours. Has the State considered the possibilities of unemployment facing direct support staff who will no longer have a full time job?

In **513.17.4 Unlicensed Residential Person-Centered Support (pp 83-87)** (the new name for ISSs), any 1:1 service over 12 hours/day must receive BMS approval. The meaning of the statement, “Approval of this level of service will be based on demonstration of assessed need not on a particular residential setting” is unclear.

During the Council's forums, families have reported that they have made long-range life plans for their family members (as is typically recommended by State and provider agency personnel) which are now in jeopardy due to the arbitrary changes to this program. How are families to plan for the future when the criteria for the program that supports their loved one is not dependable?

The statement that PCS is not available in a hospital setting is missing from Unlicensed Residential Person-Centered Support (Traditional Option) but is included again in Unlicensed Residential Person-Centered Support (Personal Options Model). Again, the Council disagrees with this limitation and believes the availability of this support should not be determined by the setting or service delivery model.

While the Council is pleased to see that other services may now be accessed on the days that **513.18.1 In-Home Respite (pp 90-94)** services are provided, it **still strongly disagrees with the 47% decrease in the allowable limits**. This is an improvement over the original 58% proposed cut, but does not allow families who may need more hours to receive them.

At least as far back as the early 1990s, the importance of this service has been recognized and the limit has been 144 hours per month. It has now been reduced to 76 hours per month. The BMS report IDDW FY2014 Final Expenditures by Service indicates less than half the individuals served by the program accessed Respite (not including Crisis Respite), and the expense equaled about 8% of the entire expenditures (Agency Respite – 7%, Personal Options Respite – 1%). This verifies the Council's continual remarks that many families simply cannot find appropriate people to provide this service. The new reduced limit will likely make it even more difficult to find people interested in providing this service.

Even for families who try to access Respite Services in order to maintain employment for themselves, a cap of 4 hours PCS and 2.5 hours of Respite Services each day does not allow for an 8 hour work day, plus travel time. The Council is very interested to learn how the Department envisions families can resolve this dilemma.

The Council suggests that the "Conflict of Interest" language be included again in **513.19 Service Coordination (pp 98-101)**. Activities listed do not reflect these points. For instance, "Provide oral and written information about the IDDW provider agency's rights and grievance procedures for persons served by

the agency.” This could potentially be an agency other than the one which employs the Service Coordinator.

The Council has repeatedly commented that BMS requires Service Coordinators to act as an advocate for the person. However, Service Coordinators do not typically have any external advocacy experience; are generally being paid by the agency in which they may need to advocate against; and have little or no specific training on how to effectively advocate for children who experience problems with the education system.

The Council is concerned that, in a program where most direct services for individuals have been cut, the caps for Service Coordination have been increased by 8 hours.

Also, caseloads have been increased from 20 to 30 people per Service Coordinator. During discussions on this issue, it was stated the case load sizes would be determined, in part, on the relative number of people who receive traditional and self-directed services. This is not reflected in the draft Manual.

513.21.3 Transportation Trips (Traditional Option) (pp 109-110) is defined as “trips to and from the person’s home, licensed Facility-based Day Habilitation Program, Pre-Vocational Center, Job Development activities or Supported Employment site or to the site of a planned activity or service which is addressed on the IPP and based on assessed need.” The limit of 2 one-way trips per day does not allow for more than one of these activities to occur. The current limit is 4 one-way trips per day. The Council disagrees with this reduction in service because the ability of individuals to be included and involved in the community will be severely hampered for those who require transportation services in an agency’s mini-van or mini-bus.

One of the **Responsibilities (p 112)** listed is, “To understand that this is an optional program and that not all needs may be able to be met through the services available within this program and a person’s annual individualized budget.” While this is true, there remains the overall obligation of the State to care for its vulnerable citizens in home and community based settings. While this program may be optional, the State would be even further out of compliance with the *Olmstead* decision and the *Home and Community Based Services Rule* if people served by the Waiver had to move to institutional settings.

A major change has been made to the **513.26 Discharge (pp 114-115)** section. Now, a person who does not access or utilize at least one direct care IDDW Service each month a person may be discharged from the program. The previous requirement was to access at least one service within a 180 day period of time.

The language says “may be discharged” for a list of reasons. What criteria will be used to determine who “will be discharged?” What about individuals who are seriously ill and hospitalized for a period of time? What allowances will be made to ensure they do not lose Waiver services while in the midst of a medical crisis?

Language in Section **513.25.3 Grievances/Complaints** raises concerns for the Council. As stated, “At no time is the amount of the annual individualized budget a matter that may be taken before the Board of Review through a Medicaid Fair Hearing. The individualized budget is assigned based on the annual functional assessment and the structured interview. The process and mathematical formulas that are used to derive the individualized budget amounts are a matter of policy and thus, are not subject to the purview of the Board of Review.” **How would an inadequate amount of funding not, in fact, cause a reduction in services and thereby be a legitimate reason to seek a Medicaid Fair Hearing?**

Finally, in answer to many concerns about services for school aged children needing services, the BMS response has been that they need to access them through the education system which is responsible for them. It is well known that families often struggle to get the basic educational needs of their children met. Needed supports such as communication devices are often not available, not provided, and not allowed to be taken home. Yet, the Department leaves it up to families to advocate for themselves against a large, bureaucratic system. It is the Council’s position that DHHR has an obligation to work within State government to change the system to ensure it meets the needs of these children prior to cutting needed services in the Waiver program.

The Council appreciates the removal of the proposed requirements for extra psychological evaluations of children at 6, 9, 12, and 15 years of age. It also appreciates that Respite Services will once again be able to be accessed on the same day as other services are provided. Job Development Services is a positive addition to this program.

The Council thanks the Bureau of Medical Services for the opportunity to express its concerns regarding this important program, which supports many of the State's most vulnerable citizens.