



West Virginia Developmental Disabilities Council

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West Virginia Developmental Disabilities Council Comments on Proposed Changes to the IDD Waiver Manual December 2017

The West Virginia Developmental Disabilities Council offers the following comments on Chapter 513, the Intellectual and Developmental Disabilities Waiver Program Manual.

~ **Pg. 8 - Program Description and 513.1 Bureau for Medical Services (BMS) Contractual Relationships** - Website addresses have been shortened/changed to links, rather than spelled out. Not everyone is accessing the Manual directly from a computer; spelling out website addresses allows individuals to type the address into a search engine. This is not consistent throughout the Manual since, for example, website addresses continue to be spelled out on pages 10-12.

~**Pg. 11 – 513.2 Provider Enrollment and Responsibilities** – The Council is pleased to see the requirements for Direct-Care Ethics training spelled out. It is important that anyone who provides direct services be knowledgeable of and adhere to “Direct-Care Ethics.” Are the related trainings also covered in the certification of professional staff?

~**Pg. 12 – 513.2 Provider Enrollment and Responsibilities, Conflicts of Interest** – The Council has no opinion on this change. While we agree it would be good to have the Member make this choice without any agency personnel in the room, we do not necessarily agree that this will “ensure complete impartiality.”

~**Pg. 26 – 513.4 Reporting Requirements** – The Council favors the shortened timeframe for entering incidents into WV IMS from 48 hours to 24 hours.

~**Pg. 28 – 513.5 Documentation and Record Retention Requirements, Specific Requirements** – The Council questions why this requirement was added. Why would a Member not be allowed to have a copy of any assessment that has been completed on them?

~**Pg. 37 – 513.8 Individual Program Plan (IPP)** – The Council has no opinion on this change, but has one question of clarification and one other comment. All

direct care service needs must be purchased first prior to purchasing additional services (except for service coordination, we assume), and if the individualized budget does not meet other identified needs, the Member may file for an exception.

Question of Clarification: What would be the process to follow if the individualized budget did not include enough funding for the direct care service needs themselves? Or if there was not enough for service coordination after the purchase of all direct care service needs?

Comment: The Council agrees that all IPP meetings should be scheduled at a time and location that takes into consideration the schedule and availability of **the person who receives services** and the other members of the team. We hear from parents that most meetings take place during work hours and/or at the offices of service agencies, which leads us to believe meetings are really scheduled at the convenience of everyone other than the person who receives services (and their family members, if applicable).

~Pg. 45 – 513.9.2 Participant-Directed Service Option – If waiver participants are to be able to self-direct their services they should be allowed to manipulate their portion of the budget in any way they see fit so long as needs are being met.

~Pg. 63 – 513.14.1 Environmental Accessibility Adaptations Home (Traditional Option) – The Council vehemently disagrees with the addition of one more limitation/cap to items that can be purchased through the EAA service. Now that, more than 25 years after the passage of the Americans with Disabilities Act (ADA), industry has responded with a variety of appliances, adaptive equipment, and technology, the DHHR plans to deny individuals with developmental disabilities access to them. Assistance is already very limited by combining three services in the \$1,000 cap [EAA Home, EAA Vehicle, and Participant-Directed Goods and Services (PDGS)]. Nevertheless, some assistance towards the purchase of items that can be very expensive is better than none. To insist that, to be covered, an item that is already designed to be accessible to people with disabilities must be further, individually, modified is difficult to understand. It is fully understood that ADA compliant items are typically also able to be used by the general population. We do not believe this means they should be excluded from payment assistance. For example, if a Waiver participant who uses a wheelchair is being taught to cook they need to be able to reach the mechanisms on a stove that control the heat. An ADA accessible stove would allow for that. Why

should the person be denied the opportunity to learn to cook for themselves just because other family members would also be using the stove? Should they have to move to a more restrictive setting to learn to cook? Might they not someday end up in a more restrictive setting because they lack independent living skills? And if the same individual could be more independent in the bathroom with a higher toilet or an accessible tub, should they be denied the opportunity to gain independence because other family members might be using the same toilet and tub? Living at home with family is not institutional living, and individuals who are able to live at home should not be discriminated against in such a manner.

~**Pg. 65 – 513.14.2 Environmental Accessibility Adaptations Vehicle (Traditional Option)** – The addition of “such as running boards” is an unnecessary qualifier to the current limitation of, “This service may not be used for adaptations or improvements to the vehicle that are of general utility (such as running boards), and are not of direct medical or remedial benefit to the individual.” While it could be argued that running boards might allow someone who otherwise would not be able to do so to step up into a vehicle, this adds to the appearance that, with each re-write of the Manual, one can expect to see other items that Members have requested added to this category (as well as in EAA Home and Participant Directed Goods and Services) for which the BMS will not help purchase.

~ **Pp. 65-72 – 513.15 Day Services** – In general, the Council is surprised and disappointed to see the changes that have been made in this section. They indicate backwards movement for individuals who receive Waiver services. The Centers for Medicare and Medicaid Services (CMS) finally began moving into the future with the announcement in 2015 that services called **Home and Community Based Services (HCBS)**, that are funded through the Medicaid Waivers, would not be provided in segregated, congregated, institutional-type settings and gave states until 2020 to transition to true home and community based services. Each state is required to develop a working plan for this transition. WV does not yet have final approval on its transition plan and is now moving backwards on its implementation.

The WV DD Council, along with other State Agency and community members, is working to move WV forward towards becoming an Employment First state. Competitive integrated employment (CIE) in locations where the employee interacts with other persons who do not have disabilities (similar to how other

people in the community typically interact), and for which an individual is compensated at or above the minimum wage, is the first option considered for how working aged people with developmental disabilities spend their days in states that follow Employment First principles.

As recent as the end of August, CMS representatives, including the Director of Long Term Services and Supports, at the national Home and Community Based Services Conference continued to reiterate that, while they are not telling states they cannot offer congregated and segregated services, they cannot be paid for with HCBS funding. We believe the HCBS settings requirements are still in effect and challenge the BMS to share with us information from CMS to the contrary.

The DD Council continues to be concerned about how people supported through the IDD Waiver spend their days outside where they live. It is recognized that working-aged people generally spend their days in work as well as other, valued life-enriching pursuits. While there needs to be a good balance of these the Council, through its Employment First Workgroup, sees that CIE is the first and preferred activity for working-aged people with intellectual and other developmental disabilities.

The Workforce Innovation and Opportunity Act (WIOA), CMS Home and Community Based Services Rule, and the *Olmstead* decision support and define integrated settings, support competitive integrated employment, and seek to reduce the use of segregated work services and settings.

The Council's Employment First Workgroup studied high performing states and found that the phase out, reduction, or closure of facility based programs is a key state program element needed to support Employment First practices. The I/DD Waiver services in each of those high performing states have been critical to increasing employment of people with significant IDD and assisting people in transitioning out of segregated facilities. Two nearby examples are the IDD Waivers in Delaware and Maryland. Delaware's IDD Waiver includes "Employment Navigators" who have specialized training and coordinate employment planning for program members based on the requirement that "competitive and integrated employment, including self-employment, shall be considered the first option when serving persons with disabilities who are of working age." Maryland's IDD Waiver provides "expanded day habilitation" services that include Employment Discovery and Customization.

513.15.1 Facility-Based Day Habilitation (Traditional Option) – The change log indicates the three-year limit for this service is being removed, but it has not been removed from the Manual. The Council objects to the removal of the three-year limit for this service unless the BMS removes the licensed site as an allowable location. The *Informational Bulletin* from the Center for Medicaid, CHIP and Survey & Certification (CMCS) dated September 16, 2011, gives the following instruction: “Day habilitation may be furnished in a variety of settings in the community other than the person’s private residence. Day habilitation services are not limited to fixed-site facilities.” It also states, “Day habilitation services may also be used to provide supported retirement activities. As some people get older they may no longer desire to work and may need supports to assist them in meaningful retirement activities in their communities.”

The Council’s position is that there is no habilitative or therapeutic justification for providing self-care, social skills training, independent living skills training and other services in a congregate setting. Regardless of any flexibility provided to states, the Council asserts that facility-based day (and other) services isolate people from the broader community. People who are unlikely to work should have access to meaningful community based non-work services that support community inclusion and integration. Such activities may support career exploration later. The provision of Day Habilitation services in typical community settings, rather than in facilities where people are segregated and/or congregated, more closely aligns with the intent of home and community based services.

The Council understands many families have faced a conundrum since the State Transition Plan was first released because they rely upon this service to give their family member a place to go during the day. Many agencies also rely upon it for that reason. **The Council does not advocate they be left with no options.** The Council believes the DHHR needs to be doing more to educate families on the changes brought about by the CMS rule, and more importantly, encouraging and assisting waiver service providers in the development of meaningful alternatives to segregated, congregated programs. Whether the DHHR/BMS believes the rule is no longer in effect or in some manner will not be enforced does not change the fact that it is the right direction in which to move. It is time to move beyond following a model that was developed during the time of widespread institutionalization of people with intellectual and other developmental disabilities.

513.15.2 Pre-Vocational (Traditional Option) – The Council objects to the removal of “and community settings” from the site of service. The previously mentioned *CMCS Informational Bulletin* provides this core service definition: “Services that provide learning and work experiences, including volunteer work, where the individual can develop general non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings.” WV uses its own definition of the service, yet it is hard to imagine how one would “achieve a path to integrated community-based employment for which an individual is compensated at or above the minimum wage...” by spending one’s time in a facility based day program.

If there is no timeframe for this service, and if, as suggested by the addition of “Persons may receive minimum wage. If the IDDW provider benefits from the person’s labor, then the person must be paid,” provider agencies can “employ” the person using pre-vocational services as the method, how will it be determined when the person should be supported to move on to actual competitive integrated employment in the community? **There do not appear to be any safeguards from keeping a person “stuck” in pre-vocational services in a licensed IDD Facility-Based Day Program while being paid by the provider to perform some sort of work for the agency.**

Evidence based practice has clearly found that “work readiness” types of activities that take place in facility-based settings are not effective in leading to integrated employment for people with significant IDD (Marc Gold and Associates, Griffin-Hammis Associates, APSE, ICI, and others). Skills and behaviors needed by a person as a prerequisite for employment should be learned in natural settings. For example, volunteering in a community setting that aligns with a person’s interests. The removal of community settings and the possibility of volunteer activities would be detrimental to this type of learning.

The Council is also interested in knowing whether there is a division of staff and space for Day Habilitation and Job Development services, since both can be offered in the same setting. Will it be possible to distinguish the difference between what each person is receiving?

Finally, if an individual is receiving training in the concepts listed as being pre-vocational services, which of those concepts qualifies as a service for which the

individual would be paid to learn? How does this differ from Supported Employment.

513.15.3 Job Development (Traditional Option) – The current policy manual leaves out, and the draft manual does not include, a critical planning service prior to job development - customized career planning that includes the Discovery process. Kentucky’s Supports for Community Living (SCL) Waiver, for example, specifies that “job development must begin with Discovery (Person-Centered Job Selection), where the job/goal features of desired employment are selected based on spending time with the person in non-standardized non-testing situations to learn his or her gifts, talents, and support needs.” Customized career planning is needed so that staff and the member are seeking and negotiating for the right job for the focus person.

The Council continues to be concerned about the lack of and types of training being required for staff who provide employment related services. **Behavior Support Professionals (BSP) and/or Registered Nurses (RN) do not necessarily have expertise in pre-vocational services, job development, or supported employment. Why would these types of professionals be required to provide training or supervise services?** As we have commented before, employment related staff must have specialized training, preferably certification, to provide such services. Any paraprofessional staff should be in a different category than staff who provide typical direct care services. **Employment is not the same as personal care and should not be treated as such.**

It is recommended that the IDD Waiver program include minimum training requirements on customized employment. The Certified Employment Support Professional (CESP) curriculum is an example of a nationally recognized training.

The Council recommends training on Social Security Work benefits be provided as an IDD Waiver service, or an assurance be made that another agency (e.g. DRS) will provide the counseling. Staff should be trained to provide general information to members and families about how SS work incentives can help people reach their employment goals and become more economically self-sufficient.

513.15.4 Supported Employment (Traditional Option) – The Council is pleased to see the restriction in site of service, which no longer allows the service to be provided in any setting owned or leased by the IDDW Provider agency, although

the concerns stated above related to payment for pre-vocational services that benefit the provider are heightened because of this change.

While some components of Supported Employment Services, such as those provided to individuals who wish to be self-employed, may not be provided in integrated community work settings, this section could be strengthened by a statement that makes clear all other employment must be in integrated community work settings.

The Council suggests the term “integrated settings” be more fully described as typical workplaces in the community where most co-workers do not have disabilities. It should also be made clear that supported employment services are predicated on the belief that persons with I/DD, including those with complex support needs, can work in the general workforce when provided with the opportunity, training, and support.

~Pg. 74 - 513.16.1 Goods and Services (Participant-Directed Option, Personal Options Model) - If waiver participants are to be able to self-direct their services they should be allowed to manipulate their portion of the budget in any way they see fit so long as needs are being met.

Also, please see comments related to accessibility given in **513.14.1 Environmental Accessibility Adaptations Home (Traditional Option)**.

~Pg. 80 – 513.17.1.2 Family Person-Centered Support (Personal Options Model) - If waiver participants are to be able to self-direct their services they should be allowed to manipulate their portion of the budget in any way they see fit so long as needs are being met.

~Pg. 95 – 513.18.1.2 In-Home Respite (Personal Options Model) – The current Manual already includes two statements apparently meant to make families aware that they receive respite in ways other than through this Medicaid Waiver funded service. The addition of extra examples of what the BMS believes families should consider as respite serves no useful purpose.

The above comment applies to all other forms of respite mentioned in section 513.18 in which those same statements have been added.

Earlier comments (Section 513.9.2) pertaining to which services can have their equivalent monetary value transferred to another self-directed service also applies here.

~Pg. 113 - **513.21.2 Transportation Miles (Participant-Directed Option, Personal Options Model)** - The Council's comments from Section 513.9.2 also apply here.

~Pp. 118-123 – **513.25.4.2 Service Authorization Process** – The Council takes issue with this new statement: “The UMC, the person, the legal representative, the service coordinator, and any other members of the IDT that wish to be present will attend the annual assessment.” We would agree to a change to the statement that said “...and any other members of the IDT that the person wishes to have present will attend the annual assessment.” Inviting everyone to attend an assessment of an individual that is sometimes very hard on the individual and/or their families, since the focus is on what the person is not able to do, is insensitive and extra people should be left to the discretion of the individual. It would also potentially make scheduling the assessment more difficult.

What is the process by which the UMC “shall resolve the issue” when there is disagreement on the assessment? The individual must notify the UMC within five days of the assessment date. What will be the timeframe in which the UMC shall resolve the issue?

In the section, **Budget Methodology** (pg. 120), a statement is made which references Section 513.25.4.2, which is the section in which the statement is located and therefore unnecessary.

The Council appreciates the transparency of the base budgets and possible add-on amounts!

In **Table 2** (pg. 120), categories are listed from lowest to highest except for those listed in Externalized Problem Behavior. We suggest these two be reversed for clarity and continuity.

In the first full paragraph following Table 2, the Council believes there is a mistake in wording. While we believe the intent was to say that no person enrolled in the program as of March 30, 2018 will have their budget cut more than 20%, the

wording appears to indicate no person will receive less than a 20% cut. The clarifying sentence which follows this statement indicates a person will receive at least 80% of their old budget, or the new calculated amount, whichever is higher.

The second paragraph, on **Pg. 121**, is a section that could benefit from having some specific examples listed. To the best of the Council's knowledge, the only "other" Medicaid services to be accessed outside the Waiver are medical care (which people would already be accessing) and possibly personal care services for those who qualify. Private insurance companies do not typically offer home and community based services; they offer coverage for health care and sometimes limited therapy services, which should already be billed prior to Medicaid. Specifically, what services does the BMS envision individuals accessing through these other means?

Redetermination Requests (pg. 121) – This section does not provide any measurable timelines for the UMC to notify the BMS of the need for an increased budget due to a documented change in an individual's status and it does not provide a measurable timeframe within which the BMS will make a final determination on increasing the budget. The Council suggests "as soon as possible" be replaced with a specific timeframe and that a specific timeframe be added as to when the BMS will render its decision.

Exceptions Process (pg. 122) – The Council does not have a recommendation as to who or what entity it should be, but believes it would be better if at least one of the three individuals on a panel to determine exceptions was not employed by, or paid through, DHHR or its contractors.

The Council takes exception to the clear statement being made that the only criterion being applied to render decisions in this program will be the provision of just enough services to "prevent a risk of institutionalization."
Who can determine such a risk?

A program designed to provide home and community based services in lieu of institutionalization of an individual should support people to live full and rich lives in their communities. We agree with the statement in the program description, which states: "The IDDW Program is a program that reimburses for services to instruct, train, support, supervise, and assist individuals who have intellectual

and/or developmental disabilities in achieving the highest level of independence and self-sufficiency possible.”

The Council remains concerned about those families who can no longer access enough hours of service to be employed full-time outside the home. Children with significant medical issues that cause them to be unable to attend school cannot access enough hours of service to allow both parents, or single parents, to work. Forcing families to use the limited respite care now available to cover the loss of hours allowed for personal care services (PCS) does not leave any respite hours available for a true respite. Despite the earlier spelling out of events the BMS believes qualifies as respite, those things do not provide the type of respite that allows caregivers to reconnect with other family members, friends, or community members. They do not allow family members living in the same household the opportunity to go out to dinner and a movie, to attend a sporting event, or any number of other opportunities families who are not providing care to an impaired family member do not have to think twice about being able to do. It appears that the DHHR would find it more desirable to cover more costly services, provided in 24 hour per day group settings, rather than support parents in their desire to keep their family intact and healthy.

The WV Developmental Disabilities Council thanks the Bureau for Medical Services for the opportunity to express its concerns regarding this very important program.