West Virginia
Developmental Disabilities Council

Comments on IDD Waiver Policy Manual
Chapter 513 Proposed Changes
April 7, 2021

The WV Developmental Disabilities Council appreciates the opportunity to provide the following comments pertaining to the proposed changes to Chapter 513, the IDD Waiver Policy Manual.

Section 513.9.2 Participant-Directed Service Option – Shouldn't the services that are being added to Personal Options model be included here? Dietary Therapy, Occupational Therapy, Physical Therapy, Speech Therapy, Environmental Accessibility Adaptations Home, and Environmental Accessibility Adaptations Vehicle are not listed.

Section 513.12.1 Dietary Therapy (Traditional Option and 513.12.5 Dietary Therapy (Participant-Directed Option, Personal Options Model) – All other therapies include a statement in the Limitations/Caps section that reads "Agency staff may not bill ___ therapy services for completing administrative activities." Is this not also applicable to Dietary Therapy?

General question regarding therapies – If Members under the age of 21 are now being required by the Centers for Medicare and Medicaid Services (CMS) to receive therapies through EPSDT rather than the Waiver, should that not be spelled out in this Policy Manual?

The Waiver allows a combined maximum of 416 units (104 hours) per IPP year for Dietary therapy, occupational therapy, and physical therapy. Are there restrictions on the number of hours allowed through EPSDT, and if so, is it more or less restrictive than the Waiver allowances? Will it be more or less difficult for families to get needed services for their children? What will Medicaid do to ensure a smooth transition? The Council asks these questions because, while we realize the intent of EPSDT is to make sure the needs of the child are met, we often hear of the difficulties families have in receiving those services, often times as a result of paperwork not being filled out exactly as required by the program.

513.14 Environmental Accessibility Adaptations – The Council is pleased to see Environmental Accessibility Adaptations (EAA) have been added to the Participant-Directed Option, but will continue to register a complaint that the combined maximum of $1,000 per IPP year to cover, home and vehicle adaptations and Participant-Directed Goods and Services is too low. We recognize a Member will not necessarily need an adaptation to both home and vehicle in an IPP year, but might, depending on the circumstances. Adaptations are generally quite expensive and $1,000 will often not cover the cost of an adaptation to a home or vehicle alone.

Participant-Directed Goods and Services (PDGS) should not be included in this combined maximum. PDGS is only available as a participant-directed service but has been included in the combined limitations/caps for the traditional options of EAA.

513.14.1 and 513.14.3 Environmental Accessibility Adaptations Home – The Council still disagrees with the limitation which disallows the purchase of adaptations that are solely ADA compliant. As we commented in 2017: "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 <u>already designed to be accessible</u> to people with disabilities must be further, individually, modified is difficult to understand. We do not believe this means they should be excluded from payment assistance."

513.15 Day Services – Most of the day services listed in this section require training of staff to be provided by a Behavior Support Professional (BSP) or a Registered Nurse (RN). These services include some that are employment related. <u>Please explain what specific training BSPs and/or RNs receive that qualifies them to train staff to provide employment related services to Members.</u>

513.15.1 Facility-Based Day Habilitation (Traditional Option) – The Council expresses its concern once again about the removal of the limit of time a Member can participate in Facility-Based Day Habilitation (FBDH) and the site of service being listed as a licensed IDD Facility-Based Day Program facility.

Although the Manual mentions a Member may access community services and activities from the licensed site, the requirement still exists that the Member must go to a segregated facility first. This actually lessens the likelihood the Member will go on to a community-based setting. This is an example of a policy that should be changed to meet the intent of a State Transition Plan for Home and Community-Based Services.

The Council realizes that FBDH facilities were not open for much of the past year due to the pandemic, but we would be interested to see any data prior to last year that showed the percentage of Members who attended a day habilitation program who arrived at the facility and then left to receive services in the community. If BMS is not collecting this data, it should be to assure HCBS funding is being used appropriately.

The Council's position, stated in the 2017 comments, 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 face a conundrum because they rely upon this service to give their family member a place to go during the day. **The Council does not advocate they be left with no options**. The Council believes the DHHR needs to be doing more to encourage and assist waiver service providers in the development of meaningful alternatives to segregated, congregated programs.

513.15.2 Pre-Vocational (Traditional Option) – The Council continues to object to the removal of "and community settings" from the site of service. The *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 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 associated 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. Is it possible to identify which service each person receives at any given time?

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?

<u>This is another example of a policy that should be changed to meet the intent of a State Transition Plan for Home and Community-Based Services.</u>

The Council's comments regarding **513.15.3** and **513.15.4** have not changed from the ones made relative to the 2017 Manual. We continue to stand by those comments. Legislation is set to pass during this session after which West Virginia will join over 30 other states in becoming an *Employment First* state. It is important that the Department's policies reflect and support the philosophy of *Employment First*.

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."

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.

513.18 – Respite – In a recent survey by the Council, respite care was the service most mentioned as needed and unable to be obtained. Respondents say there are not enough hours allowed to meet their needs and/or they are not able to find respite providers. Respondents have delayed needed surgery because of a lack of respite. Several respondents mention the cut in allowable hours has made their lives harder and has also made finding a respite care provider harder because people do not want to work the small number of hours allowed.

The Council believes there is no useful purpose in the Department using a policy Manual to inform families as to what they believe are the various forms of respite they receive (other than the formal Waiver service). It is an opinion, not a policy, and does not belong here. It is inappropriate and offensive to assume what is or is not a form of respite for a family providing care to an individual who qualifies for this program. This was added to the Manual when respite hours were cut drastically, apparently as an attempt to justify the cut. It should be removed.

Why is there a requirement for documentation if a BSP is involved in training plans for the Personal Options models of Respite but not for the Traditional models?

513.19 Case Management – The first item in Limitations/Caps states the amount of service is limited by the member's individualized budget, but case management is a mandatory service and the PMPM rate has been established by the Department.

The Council understands conflict-free case management (CFCM) has been required by CMS and can no longer be ignored by WV, however, we have some concerns about the plans for implementation.

Although the per Member per month (PMPM) rate for Members living with family is less than for Members living in other settings ($200 rather than $250), some Members may be hurt by having this amount deducted from their budget, whether or not they need or use $200 worth of service.

The Council has advocated a flat rate for these services for at least two decades, but there are no controls in place to encourage good case management. These are some concerns we have and some we have heard from providers:

- Many providers say the rates are not high enough to provide the service. Apparently, rates were determined using billing history from previous years, but those rates were not covering the cost of providing the service and CFCM agencies will not be providing other services to help make up the difference. Based on the job requirements, case managers are required to fill the role of social worker, accountant, and advocate. The Department should consider looking at the prevailing wages in these careers to set a fair rate.

- The service includes a two-page list of activities a case manager must perform and another page of limitations and caps, some of which appear to be in conflict. For example, in listed activities, case managers are required to upload certain documents into the Utilization Management Contractor's (UMC) web portal, along with any additional documentation BMS or the UMC may request, but in limitations/caps a case manager cannot bill for Utilization Management activities.

- Some provider agencies have, in the past, acted as representative payee for Members they serve. Case management agencies are now prohibited from performing this service for Members for whom they provide case management. We are not aware of how many agencies may have decided to become strictly case management agencies now. Were they aware of this restriction prior to making this decision? If they were representative payees for Members who will continue to receive case management services from them, how long will Members have to find new representative payees?

- In a power point presentation on the Bureau's CFCM webpage, Ed Kako and Robin Cooper state case managers should engage in high quality, person-centered planning (PCP) that keeps the full focus on the person, and that PCP depends heavily on quality case management. They go on to state caseload sizes that match scope of responsibility and account for the level of

support individuals will need are a requisite for good case management. The Council believes the Department should do more to encourage true PCP and to ensure case managers and others are trained in the use of PCP. The Council also disagrees with the lack of any requirements for caseload size. Since the rate of pay is considered low by many providers and apparently little oversight is planned, it seems likely agencies will be inclined to take on larger caseloads in order to be able to afford to provide the service. Members will suffer because of this.

- The Policy Manual does not speak to the possibility of exceptions to CFCM. It is our understanding that exceptions could be made for remote, rural areas or for cultural/linguistic reasons. If the Department has such a policy, it should be spelled out in this manual. More than a link to the WV Department of Arts, Culture, and History showing ethnic regions should be provided to explain what the Department interprets as "culture."

And finally, concerning policy. Where does one look to find IDDW policy that is not spoken to in this Policy Manual? For instance, some forms associated with this program indicate there is policy associated with a question, but that information does not appear in this Policy Manual. Is there another Policy Manual associated with this program, and where might one expect to find, for example, the remainder of the policy on EAA – Vehicle?