

WV Developmental Disabilities Council
Comments on Draft Chapter 513
Covered Services, Limitations, and Exclusions for I/DD Waiver Services

The WV Developmental Disabilities Council has reviewed and offers the following comments on Draft Chapter 513 for I/DD Waiver Services.

Comment on language: Throughout this document references are made to “mental retardation.” Both the Federal and State government have passed legislation to change this terminology to “intellectual disability.” Generally, all Federal programs are using the new language on websites, new documents, and other communications about programs they administer. Although not all Federal programs have been able to change the nomenclature in all sections of Code at this time, perpetuation of the incorrect term should not be used in a Manual being updated after the passage of the legislation.

General Comment on Participant-Directed Services: The Council is disappointed to see so few services included in this category, and believes that several more of the “professional” services could also be participant-directed, which would truly give individuals more choice and control over the services they need and want.

In particular, the Council would like to see Supported Employment services be available in the participant directed array of services. As the Manual is currently written, there are no special qualifications needed by an employee supporting a member on the job. This in itself should make it feasible for the service to be participant directed.

The Council strives to fund projects and endorse policies that will increase the employment of individuals with developmental disabilities in our State. WV consistently ranks at or near the bottom of states in the nation in the employment of individuals with developmental disabilities. Allowing waiver members to self-direct their own employment options, along with less burdensome licensing restrictions on supported employment providers, could potentially help to increase the likelihood that more individuals could find employment.

Specific Comments

513.1 Definitions:

The DD Council comments on each Draft that the definition used for Developmental Disability is incorrect and incomplete. The Federal definition can be found *P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000*. The definition does not include specific conditions, does include seven major life activities rather than six, and includes specific criteria for children up to age nine.

The definition is as follows:

(8) DEVELOPMENTAL DISABILITY.-

(A) IN GENERAL. -The term "developmental disability" means a severe, chronic disability of an individual that-

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN. -An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

The definition for Human Services Field Degree includes several fields, such as Political Science, that have little or no relevance to the provision of services to individuals with developmental disabilities. The Council is particularly disturbed to see the field of Criminal Justice included in this listing. One of the many wounds that individuals with developmental disabilities incur is the perception that they are dangerous, or a threat to others. The inclusion of the field of Criminal Justice as an acceptable degree for working with Waiver members perpetuates the idea that they are dangerous. It seems conceivable that individuals trained in Criminal Justice are more competent to work with criminals than vulnerable people and may have been taught approaches that would be detrimental to Waiver members.

There is no definition listed for intellectual disability. Please see below the definition in WV State Code.

The definition of *Intellectual Disability and Developmental Disability (I/DD) Waiver Program* includes the following sentence: "OHFLAC provides monitoring and supervision of members' health and welfare as well as oversight of I/DD Waiver providers." The DD Council believes this is an inaccurate statement, as OHFLAC only provides monitoring and supervision of members who reside in licensed facilities, not those who live in family homes. Furthermore, the DD Council would not approve of the extension of OHFLAC oversight to private settings such as family homes.

The definition of mental retardation given cites WV Code, which has been changed as follows:

§27-1-3. Intellectual disability.

"Intellectual disability" means significantly subaverage intellectual functioning which manifests itself in a person during his or her developmental period and which is characterized by his or her inadequacy in adaptive behavior. Notwithstanding any provision to the contrary, if any service provision or reimbursement is affected by the changes in terminology adopted in the 2010 First Extraordinary Session of the Legislature, the terms "intellectual disability" or "individuals with an intellectual disability" shall assume their previous terminology. It is not the intent of the Legislature to expand the class of individuals affected by this terminology change.

The name of OHFLAC is incomplete. It should read Office of Health Facility Licensure and Certification.

513.2 Program Description:

The first sentence uses the term “intellectual disability,” while the third sentence uses the term “mental retardation.” Please note the previous comment provided on language. Further comment on this language issue will not be made, but the Council maintains the entire document should refer to the current legal language of “intellectual disability.”

513.2.2.1 Additional Qualifications for Traditional Option Agency Staff and Participant-Directed Option Agency with Choice Model Staff:

The Council understands and agrees with the removal of the requirement for a high school diploma or GED for family members who are providing services to their own family member Waiver participant. However, as was commented on in the draft Waiver application, the Council cautions that this relaxation for employees other than families could also contribute to the erosion of the quality and training of a workforce that is already troubled in this regard. The Council would like to see this requirement put back in place for employees other than family members.

513.2.3 Reporting Requirements: Is there no definition of **Abuse, Neglect and Exploitation Incidents** available that apply to individuals under the age of 18? The definition given only applies to incapacitated adults.

513.3.2 Initial Medical Eligibility: The need to meet eligibility criteria for “the need for active treatment” does not fit with discussions held during the many meetings of the workgroup that addressed the self-directed option. Workgroup members were told the Centers for Medicare and Medicaid Services (CMS) no longer required active treatment as a criteria for receiving Waiver services. Since active treatment is no longer a requirement for the program, the need for active treatment should not be an assessed requirement for medical eligibility criteria.

513.3.2.2 Functionality: According to the Federal definition (mentioned earlier) of developmental disability, there are seven identified major life areas which are to be assessed. This list excludes “economic self-sufficiency.” The DD Council believes that a program designed to provide services to individuals with developmental disabilities should use the correct definition and include all the major life areas listed in the definition.

The definition of “substantial deficits” remains the same as that commented on in recent years, and is hard to understand. It also remains one of the most restrictive definitions in the country used for waiver eligibility. The DD Council remains opposed to this very restrictive definition.

513.3.2.3 Active Treatment: See comments given for **513.3.2**. It is the understanding of the DD Council that “active treatment” is no longer a required component of this program, per CMS directive.

513.3.3.1 Initial Financial Eligibility: If an applicant and/or legal representative has completed the application form (DFA-1 or DFA-LTC-5) with an Economic Services Worker at their local/county DHHR office, and it is approved, how would they then be held responsible for ensuring “the system” does its job properly? How will an applicant and/or their legal representative know how to assure they are properly coded in the DHHR Recipient Automated Payment and Information Data System (RAPIDS) in order for payment for the medical services to occur? Who would they ask to speak with? What would they ask? How would they know what the correct answer should be?

513.3.4 Slot Allocation Referral and Selection Process: The Council questions the fairness of using a Medicaid Fair Hearing date as the slot allocation date for an individual who is established as eligible as the result of a hearing. The individual should be placed on the list retroactive to the date they would have been added if not deemed ineligible originally. The placement on the slot allocation list could potentially make a difference in whether an individual would have to wait an additional year for services.

513.3.5 Eligibility Effective Date: If either the member or their service coordinator must provide the letter to the ASO from DHHR approving the applicant for financial eligibility, how will either know the other did so? This requirement, along with the requirement listed in **513.3.3.1**, seem more appropriate as functions of a service coordinator. Service coordinators have a more direct line of contact with the ASO than does a member.

513.4 Member Eligibility and Enrollment Process: The same comments as those mentioned in **513.3.2.2** apply to this section.

513.4.1 Annual Re-determination of Medical Eligibility: Fair Hearing and Pre-Hearing Conference should be defined in **513.1 Definitions**.

513.4.2 Annual Re-determination of Financial Eligibility: In the current waiver, the State notifies the member's local DHHR of medical re-eligibility and the Economic Service Worker contacts the individual/family to make an appointment for the re-determination of financial eligibility. This draft Manual only mentions that Waiver members must have their eligibility re-determined annually. Will the same process for notification as in the past take place?

513.5.1 Member Rights: It is the Council's understanding that not all members have a choice between Traditional and Participant-Directed Service options or a combination of both. Participant-directed services will not be available to members living in OHFLAC licensed residential settings or other congregate settings per **513.9.2**. This exception should also be listed in this section for clarity.

513.5.2 Member Responsibilities: Natural supports should be defined in **513.1 Definitions**.

As written, this section would seem to imply that 'natural supports' have the same responsibilities as those paid to provide services under this program, and that a member's services might be in jeopardy if the 'natural support' does not participate in or do the things listed. The DD Council does not agree that 'natural supports' can be held to these same standards.

513.5.3 Member Grievances/Complaints: The Assessment Data Modification Request form (WV-BMS-I/DD-13) is not included in the Chapter 513 I/DD Waiver Forms. This will also be noted in DD Council comments on forms.

513.5.4 Member Appeals: The DD Council suggests that the third paragraph (related to submitting the Request for Hearing form within 13 days) be combined with the first paragraph as it is in **513.4.1**. This would provide a clearer understanding of the time frames for submitting the form under each circumstance, rather than separating the two time frames by information for seeking a second psychological evaluation.

513.6 Member Discharge: Under the third bullet (reason for discharge) it is stated that if a member voluntarily terminates Waiver services, the Service Coordinator must convene the IDT in the development of the IPP to transition the member to new services. If a member decides not to participate in the Waiver any longer, the Council is interested in knowing what new services would be available for them to access. The Council is quite concerned about what services would be available to individuals who are discharged from the program, as well as services for those who are judged to be ineligible for the program.

Regarding bullets five and six (failure to comply with policies or not accessing services for six consecutive months), what steps will be taken to inform/advise the member prior to a request to the ASO to discontinue services?

The DD Council is pleased to see the prohibition against discharging or discriminating against a member and/or their legal representative or employee who has been a complainant, on whose behalf a complaint has been submitted, or who has participated in an investigation process involving the I/DD Waiver provider.

513.7 Member Transfer: The DD Council is very pleased to see that an I/DD Waiver provider may not terminate services unless a viable IPP is in place that effectively transfers needed services from one I/DD Waiver provider to another provider and is agreed upon by the member and/or their legal representative and the receiving provider. Assuming appropriate oversight is put into place to ensure this, it should help to resolve the issue of provider of last resort.

513.8.1 The Interdisciplinary Team (IDT): The DD Council is pleased to see the continued requirement that IDT meetings should be held in a location that is convenient to the member. However, what oversight is in place to assure this? The DD Council has heard regularly over the past several years that meetings are still being scheduled and held in locations for the convenience of the professional team members, and not for the member and his/her family.

In most instances, the requirement of a Medley Advocate on the IDT for Medley Class members is a good safeguard. However, the DD Council wonders about the necessity of this requirement for Medley Class members who have a family member as a legal guardian.

513.8.2.1 Seven Day IDT Meeting: The statement that “meeting documents must reflect a full range of services: Medicaid, non-Medicaid, and informal or natural supports” may not be possible to meet. What will happen for Waiver members who do not have non-Medicaid, informal, or natural supports? Will the document not be valid if all these components are not included?

Sections **513.8.2.2, 513.8.2.3, and 513.8.2.4** all list those who must be in attendance; as well, **513.8.1** lists the minimum members of an IDT. Necessary members are not listed for the seven day IDT meeting. Who will they be?

513.8.2.3 Transfer IDT Meeting: This refers to when a member wishes to change Service Coordination providers. Does the same process occur when a member wishes to change providers of other Waiver services besides Service Coordination? If not, what would be the process for doing so?

513.8.2.4 Critical Juncture Meeting: This section includes a paragraph related to when a member transfers from one residential or day setting provider to another. Should it not be included in section **513.8.2.3 Transfer IDT Meeting** instead?

513.8.2.5 Annual, Quarterly and Six-Month IDT Meetings: The DD Council is pleased to see continued the option of six-month IDT meetings in lieu of mandatory quarterly IDT meetings.

513.9 Description of Service Options: The DD Council commented previously, and comments again on the statement that there are two Financial Management Service (FMS) models available to members who choose the Participant-Directed Service Option.

Although DD Council staff and Members have heard various agencies state that this model is quite similar to how they currently operate, no agency has been heard to say they intend to participate in this model. Some have said they will not. Agencies interested in providing this option must apply to and be approved by BMS. Will this process occur prior to the implementation date of the Waiver? Will there be any incentives to encourage reluctant providers to apply? How does the Bureau plan to ensure the Agency with Choice (AwC) FMS model will be available as an option?

513.9.1.1 Behavior Support Professional: Traditional Option: The Council is happy to see the re-insertion of Positive Behavior Support as a service in the program and the inclusion of qualifications for providers of the service.

Definition of Service: The third paragraph states “I/DD Waiver provider agencies...may allow their agency staff...to bill the BSP code as long as they meet all other requirements above.” There do not appear to be any staff requirements listed prior to that statement, although Agency Staff Qualifications are listed two pages later in this section.

Agency Staff Qualifications: Are the individuals listed in the third bullet (BA or BS degree in human services and two years experience in the I/DD field and documented evidence of enrollment in the APBS standards of practice coursework) the same individuals referred to in **Definition of Service** (formerly credentialed as Therapeutic Consultant Behavior Analysts or Therapeutic Consultant Behavior Specialists)? If not, will individuals who have not completed coursework be billing at the same rate as those who have? Will some Waiver members who need BSP services be receiving those services from someone not properly trained to provide them until January 1, 2013?

513.9.1.4 Electronic Monitoring/Surveillance System and On-Site Response: Traditional Option: The DD Council has expressed its disagreement with electronic monitoring and surveillance systems continuously since a vendor first came to WV to pitch such products. It is disturbing to see that many of the ‘safeguards’ that were mentioned previously are not in this draft Manual, i.e., no surveillance equipment in bedrooms and bathrooms.

The DD Council continues to be opposed to this method of providing services to individuals using the Waiver program for a variety of reasons, including philosophical ones. The safety reasons for opposition include a concern for what happens during power outages, and the very likely potential for a breakdown in the plan for stand-by staff response when an emergency occurs.

Not only are breakdowns in the staff response likely to occur, the time frames listed (within 20 minutes from the time an incident is identified by the remote staff and the stand-by staff acknowledges receipt of the notification by the remote staff)

are unacceptable in an emergency situation. The qualifiers listed mean a response time could be an hour or longer.

This opposition should not be construed as the DD Council believing all Waiver recipients need 24 hour support. The Council does believe that some Waiver recipients are quite capable of maintaining their own health and safety for periods of the day and should be afforded the opportunity for independence and privacy when they have that capability without jeopardizing their eligibility for this program.

513.9.1.5.1 Environmental Accessibility Adaptations: Home: Traditional

Option: The DD Council has repeatedly commented over the years that the \$1,000 cap on this service is quite low when considering the cost of many adaptations. By combining an already low cap on this service with Environmental Accessibility Adaptations for the Vehicle and with Participant-Directed Goods and Services, many individuals will not be able to purchase either accessibility adaptations or goods and services they may need.

The Council disagrees with the inclusion of fences in the limitations/caps section. Many, possibly even most, homes do not come with fences. For families whose Waiver member has a history of running, a fence absolutely should be considered as an environmental accessibility adaptation.

The DD Council also finds it perplexing that, while this program is willing to cover electronic monitoring and surveillance, it excludes here security systems which also might be a safety feature in homes where the waiver member has a history of running away since they can be set to alarm when a door is opened.

513.9.1.5.2 Environmental Accessibility Adaptations: Vehicle: Traditional

Option: See comments under **513.9.1.5.1** related to combining caps.

513.9.1.6 Facility-Based Day Habilitation: Traditional Option:

Site of Service: How would facility-based day habilitation be provided in a public community setting?

Definition of Service: The Council is happy to see the requirement that facility based day habilitation services must be based on assessment, be person-

centered/goal oriented, and be meaningful/productive activities that are guided by the members' needs, wishes, desires, and goals. It has been the Council's experience that facility based day habilitation programs are not any of those things, rather, they are poorly designed and implemented "sitting" services. The Council is concerned with how this be monitored and measured.

The Council also suggests the addition of the word "strengths" to the list which now includes members' needs, wishes, desires, etc.

513.9.1.7 Occupational Therapy: Traditional Option:

Limitations/Caps: The combination of a 104 hour annual cap which also includes Physical Therapy and Dietary Therapy may not be sufficient for the need for individuals for chronic conditions and maintenance. 104 hours equate to two hours per week, which may be sufficient to cover weekly physical and occupational therapy. However, this would leave no time available for dietary therapy although it would only be an occasional service.

513.9.1.8.1 Person-Centered Support: Agency: Traditional Option:

Limitations/Caps: The DD Council is opposed to the limitation that PCS: Agency services are not available while a member is hospitalized except when the behavioral needs of the member arise due to the temporary change in environment. It is the position of the Council that no person should be left without external supports while hospitalized to ensure their safety and well-being, and vulnerable individuals (such as Waiver members) are in particular need of such supports while hospitalized.

The Council would be pleased to see Respite Services used in this setting rather than PCS, but that is also not allowed per **513.9.1.10.1**.

513.9.1.9 Physical Therapy: Traditional Option: Same comment as in **513.9.1.7**.

513.9.1.10.1 Respite: Agency: Traditional Option:

Limitations/Caps: See comment related to hospital exclusion under **513.9.1.8.1**. The DD Council would like to see the following language from the current Waiver Manual re-instated in this draft:

A general medical hospital when the member warrants the need for additional assistance by a

familiar staff person that would not otherwise be provided by hospital staff.

What is the meaning of the statement that Respite services are not to replace natural supports available to the member? If a family member is a member's natural support, respite services, by their very nature, are meant to replace that support in order to allow the family member a break.

What does 6,912 units per year **combined with all direct care services available in the Traditional Option** mean? The Council sincerely hopes this addition was a clerical error. If this is intended to mean that the traditional 144 hours of Respite available per month are now decreased by each hour of other service provided, the Council is vehemently opposed.

513.9.1.11 Service Coordination: Traditional Option:

Limitations/Caps: It is the understanding of the Council that CMS allows for the billing of service coordination up to 180 days prior to discharge from an institutional setting; therefore it disagrees with the 30 day cap placed on it for this program.

513.9.1.13 Speech Therapy: Traditional Option: The DD Council is pleased to see that Speech Therapy events are not combined with OT/PT/Dietary Therapy services for caps/limitations!

513.9.1.14 Supported Employment: Traditional Option:

Site of Service: Rather than "may," the Council would like to see "This service must be provided in an integrated community work setting," recognizing that the vocational counseling component might not occur in any type of work setting.

Limitations/Caps: The DD Council is very pleased to see the cap for this service set at 40 hours per week, which is a typical work week. However, the combination of this cap "with other direct care services available" seems to imply that individuals cannot receive more than 40 hours per week in total services. Individuals on the Waiver program have a high likelihood of needing more than 40 hours per week of services.

This section is very confusing in its entirety. If the maximum annual units of supported employment cannot exceed 8,320 units (in the fourth bullet), why are

units of 11680, 17520, and 35040 listed in the next three bullets? If the higher units listed are meant to denote the total number of hours inclusive of all services received, the fourth bullet (which is commented on in the preceding paragraph) should be re-written to exclude the sentence referring to the limit combination.

The ability to use 12 hours of SE services every three months for member-specific instruction of staff seems excessive. Is it anticipated that SE staff will turn over on a quarterly basis?

The Council strongly opposes the exclusion of Supported Employment Services from the participant-directed services option.

513.9.1.15 Therapeutic Consultant: Traditional Option:

Agency Staff Qualifications: If job placement activities are going to be a service offered by Therapeutic Consultants, what specific training/qualifications will they be required to have in order to accomplish this?

513.9.1.16 Transportation (in each option): The Council is pleased to see the relaxation in transportation such that the service is not strictly limited to a Member's own community.

513.9.2 Participant-Directed Services: Please explain the reason for the restrictions listed for a member's legal representative being allowed to also provide services to the member. The DD Council, along with the DHHR and others, worked to change the guardianship legislation during the last session to allow guardians to be providers of service to their family members under this program. There are no restrictions applicable only to single parents in the legislation that was passed. **By whose authority does BMS add the restriction causing the revised State law to apply only in the case of a single parent?**

It is understandable that those choosing the participant-directed services option also have the traditional service option available to them for other needed services. However, the Council does not agree with the statement requiring all other services be purchased through the traditional service option prior to purchasing any services through the participant-directed services option. Why are the four services available under the participant-directed option considered of lesser importance than traditional service options?

The Council believes that all needed services are of equal importance, and relegating participant-directed service options to a lower priority, in effect, makes them seem optional. This is not the Council's understanding of the purpose of allowing participant directed services in this Waiver program.

Assuming an individual's needs have been well assessed, and a budget appropriately derived based on those needs, there should be money in the budget to purchase needed services whether they be participant-directed or traditional. If not, negotiations with the ASO should take place to adjust the budget to meet the Waiver member's needs.

513.9.2.1 Participant-Directed Services Option: Agency with Choice Model:

Is there a cost to the Member for the use of services provided with the AwC model? If so, the cost is not mentioned here, nor is a fee listed on the Service Codes and Rates. **If there is a cost for the use of this service, please include it in this Manual so Waiver participants will be aware when choosing this model.**

513.9.2.1.5 Respite: Participant-Directed Option: Agency with Choice Model:

Limitations/Caps: See comment related to hospital exclusion under **513.9.1.8.1**.

The DD Council would like to see the following language from the current Waiver Manual re-instated in this draft:

A general medical hospital when the member warrants the need for additional assistance by a familiar staff person that would not otherwise be provided by hospital staff.

This comment applies to all sections of this draft Manual that relate to Respite Care.

513.9.2.2 Participant-Directed Services: Fiscal Employer Agent Option: Is there a cost to the Member for using the FEA? If so, the cost is not mentioned here, nor is a fee listed on the Service Codes and Rates. **If there is a cost for the use of this service, please include it in this Manual so Waiver participants will be aware when choosing this model.**

513.9.2.2.1 Qualifications for Qualified Support Workers: With the exception of First Aid and CPR, which are readily available through the ARC or AHA, where

would individuals choosing to use Participant-Directed Services access the trainings required for Qualified Support Workers (QSW)? Will the FEA be responsible for providing this training to the QSWs?

Furthermore, the Council can think of no circumstances under which a Waiver Member would want to hire a Qualified Support Worker and then have the worker trained in the use of restraints against themselves.

In many, if not most, circumstances the QSW will be a family member who has been providing residential habilitation services to their Waiver family member already. Under such circumstances, why would they now need to have many of these trainings that they have never been required to have in the past, i.e., Infectious Disease Control, Crisis Intervention, etc.?

513.9.2.3.3 Respite: Participant-Directed option: Fiscal Employer Agent Model:

Limitations/Caps: Why is the QSW to member ratios for this service capped at 1:1 when Respite under other models is capped at 1:2? Is it not likely that individuals choosing the FEA model are similar to, and have similar needs as individuals choosing the AwC or the traditional service option model? Specialized Care Homes as well as family homes may include more than one Waiver member.