West Virginia
Developmental Disabilities Council

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October 13, 2023

Randy Hill, Office Director
Home and Community Based Services
WV DHHR Bureau for Medical Services
350 Capitol Street, Room 251
Charleston, West Virginia 25301

RE: I/DD Waiver Application Comments

[Delivered via email to iddwcomment@wv.gov]

Dear Mr. Hill:

The WV Developmental Disabilities Council is a 31-member organization consisting of citizens with developmental disabilities, family members, and representatives from State and private organizations concerned with the provision of services to people with developmental disabilities. Over 60% of the membership are citizens who are appointed by the Governor.

The mission of the Council is to assure that West Virginians with developmental disabilities receive the services, support, and other forms of assistance needed to achieve independence, productivity, integration, and inclusion in the community. One of the ways the Council carries out its mission is to provide information to policymakers on issues that may affect people with developmental disabilities.

Thank you for the opportunity to comment on the 5-year Waiver Renewal Application for the I/DD Waiver. This Waiver is essential to support people with developmental disabilities in their home and community. The federal government offers this waiver option to eliminate and/or prevent institutionalization. It is critical to meeting the State's obligation under Title II of the Americans with Disabilities Act (ADA) to provide services in the most integrated setting in the community as upheld by the U.S. Supreme Court decision in *Olmstead v. L.C., et al.*

Below are comments to assist the Bureau in submitting a waiver application to best meet the needs of people with developmental disabilities to be supported in a person-centered manner to live, work, socialize and thrive in their home and community.

The Council's comments are categorized into 3-parts:

A. Areas of concern.
B. Areas of potential benefit.
C. Areas that raise questions.

PART A – AREAS OF CONCERN

The Council would like to address **six areas of concern** that may prevent people with developmental disabilities from receiving services they need for full integration and inclusion in their home and community. **These areas of concern include:**

1. Waiver eligibility criteria of substantial deficits of three standard deviations below the mean.
2. Eliminating Autism Spectrum Disorder (ASD) I and II from eligibility criteria.
3. Inadequate slot allocations over the next five years to eliminate and/or reduce a waiting list.
4. Excessive institutionalization requirement for access to a waiver slot under the *Benjamin H.* class action suit settlement agreement and under At-Risk Case Management.
5. Quality of Life language
6. Skilled Nursing Medication Administration

PART A – CONCERN #1: WAIVER ELIGIBILITY CRITERIA – STANDARD DEVIATIONS

Appendix B-1, Page 32:

Substantial deficits are defined as standardized scores of three standard deviations below the mean or less than on percentile when derived from a normative sample that represents the general U.S. population or equal to or below the 75th percentile when derived from intellectual disability normative populations. While this is not a new change in the waiver application, it remains a serious concern to the Council.

The Council reviewed the medical eligibility criteria for the intellectual and/or developmental disabilities waivers of all other 49 states and the District of Columbia. **The findings were clear that no other state or district of the United States uses such a restrictive substantial deficit criterion.** All other states use the definition of intellectual and/or developmental disability found in federal law and/or the Diagnostic and Statistical Manual (DSM-5) which identifies two standard deviations from the mean.

The Council **recommends** the Bureau use the federally and nationally recognized definition of intellectual and/or developmental disability of two standard deviations of the mean.

PART A – CONCERN #2: WAIVER ELIGIBILITY CRITERIA – AUTISM SPECTRUM DISORDER (ASD)
Appendix B
Appendix B-1, Page 31-32 and Appendix B-6, Page 46:
This proposed waiver application specifies Level III as an initial medical eligibility requirement for autism spectrum disorder (ASD) as an example of a related condition for eligibility. In previous waiver applications, the term used is autism. This waiver application appears to eliminate members who have Level I or Level II ASD. Autism is not checked as a target group. Twenty-seven (27) out of 45 states (or 60%) specify autism (with no delineation on level of ASD) or have a specific autism 1915(c) waiver. Five (5) states were not included in this research because they implement 1115 demonstration waivers. States with autism-specific waivers: Arkansas, Connecticut, Kansas, Maryland, Massachusetts, North Dakota, and Pennsylvania.

The Council **recommends** the Bureau leave the criteria as it has appeared in previous applications as a related condition of autism or check autism as a target group.

PART A – CONCERN #3: WAIVER SLOT ALLOCATION
Appendix B-3, Page 35:
The waiver application maintains the previous level of unduplicated number of participants for the first year of 5,964. The application increases the number of unduplicated participants for years 2 through 5 to 6,114. This equates to an increase in 150 slots over the new 5-year waiver period.

The Council **recommends** the Bureau project an adequate level of slots needed over the 5-year period to meet the needs of people who require and are eligible for this service.

PART A – CONCERN #4: LENGTH OF INSTITUTIONALIZATION REQUIREMENTS
SLOTS FOR BENJAMIN H
Appendix B-3, Page 36:
Benjamin H. slot eligibility where adults must be institutionalized for 6 months; and children must be institutionalized in an out of state facility for 6 months. There are 6 slots allocated for adults and 6 slots allocated for children who meet this requirement.

The Council **recommends** removing the 6-month institutionalization requirement. This requirement likely will cause individuals to be institutionalized longer than is necessary or appropriate. This is an improvement from the current waiver application because it decreases the length of time a child must be institutionalized from one year to 6 months.

AT RISK CASE MANAGEMENT

Appendix C-1/C-3: Service Specification: At Risk Case Management, Page 55-58:

The purpose of this service is to ensure Waiver services are in place day one of the member's transition to the community from an institutional facility, and to assist in preventing institutionalization for members at risk.

Individuals eligible for this service must live in (or be at risk of) a nursing facility, hospital, correctional facility, institution for Mental Disease or a combination of any of the three for at least six months.

The Council **recommends** adding intermediate care facilities for individuals with intellectual disabilities (ICF/IID) and institutional setting that meets the federal CMS definition of institution. The Council also **recommends** removing the 6-month requirement.

PART A – CONCERN #5: QUALITY OF LIFE

Quality of Life Language: Page 2, 3, 64, 79, 81, 168

The Council understands Appendix H of the CMS Waiver Application addresses the "Quality Improvement Strategy" or "Use of a Patient Experience of Care/Quality of Life Survey." As a result of this CMS language, the Bureau has included the use of the "quality of life" language.

It should be noted that the CMS language also uses the term "patient." The Bureau does not use this language to refer to members receiving IDD Waiver services. The Council would like the Bureau to adopt different terminology. The Council **recommends** replacing "quality of life" language with: "Quality of Services Assessment" or "Quality of Service Delivery Assessment."

"Quality of life" or QOL is not a medical term and has no agreed upon definition. QOL has become a term used in the medical field, often to determine who should receive treatment and who should not. Medical personnel are left to their own feelings and beliefs to decide what they believe the "quality" of someone's life is currently, or what it may become in the future, and therefore, whether an individual is worthy of treatment or not.

To provide more clarity on the reasoning for this comment a link is provided to a position paper about the dangers of the term "quality of life" on the Council's website: https://ddc.wv.gov/publicpolicy/Documents/Position%20Papers/Quality%20of%20Life%20Opposition%20to%20Bill%20Jan%202018.pdf

PART A – CONCERN #6: SKILLED NURSING MEDICATION ADMINISTRATION

Appendix C-1/C-3: Skilled Nursing Medication Administration, Page 123-124:

The service definition states, "Skilled Nursing Medication Administration provides the administration of oral, intramuscular, and/or subcutaneous medication by a licensed healthcare professional, as prescribed and ordered by a physician, to the member."

There are other methods for administering medication. As this is written, Approved Medication Assistive Personnel (AMAPs) have authority for additional medication administration routes than a skilled/licensed nurse.

The AMAP statute defines medication administration routes as, "Medication means a drug, as defined in section one hundred one, article one, chapter sixty-a of this code, which has been prescribed by a health care professional to be ingested through the mouth, inhaled through the nose or mouth, administered through a gastrostomy tube, applied to the outer skin, eye or ear, or applied through nose drops, vaginal or rectal suppositories."

The Council **recommends** the Bureau change this language to state skilled nurses may administer medications within the scope of their practice under State law and rule.

PART B – AREAS OF POTENTIAL BENEFIT

The Council would like to identify **six areas of the waiver application that can potentially benefit members** and their right for integration and inclusion in their home and community. These include:

1. Addition of At Risk Case Management services.
2. Qualifications for Case Manager.
3. Behavior Support Professional.
4. Crisis Intervention Services.
5. Medley advocate added as an IDT member.
6. Increase in anticipated personal options members.

The Council appreciates the Bureau's inclusion of these changes in the renewal application.

PART B – POTENTIAL BENEFIT #1: AT RISK CASE MANAGEMENT

Appendix C-1/C-3: Service Specification: At Risk Case Management, Page 55-58:

The purpose of this service is to ensure Waiver services are in place day one of the member's transition to the community from an institutional facility, and to assist in preventing institutionalization for members at risk.

This service may be billed for up to 100 units or 25 hours.

PART B – POTENTIAL BENEFIT #2: CASE MANAGEMENT QUALIFICATIONS

Appendix C-1/C-3: Service Specification: At Risk Case Management, Page 55-58:

At Risk Case Management qualifications include a new provision for someone with 5 years of experience in the WV IDD Waiver field in lieu of a four-year degree in the human service field with restrictions. The restriction is the provider must be under the supervision of the case manager supervisor for 6-months.

Appendix C-1/C-3: Service Specification: Case Management, Page 58-62:

Case Management qualifications include a new provision for someone with 5 years of experience in the WV IDD Waiver field in lieu of a four-year degree in the human service field with restrictions. The restriction is the provider must be under the supervision of the case manager supervisor for 6-months.

PART B – POTENTIAL BENEFIT #3: BEHAVIOR SUPPORT PROFESSIONAL

Appendix C-1/C-3: Behavior Support Professional, Page 78-81:

Modified scope of work for Behavior Support Professional (BSP).

Current policy has BSP IIs as requiring APBS endorsement, and the new policy will require all BSPs to obtain APBS endorsement. BSP Is will be given until July 2025 to comply.

The application defines the differences between BSP I and BSP II in more detail. Qualifications of BSP Is and BSP IIs are now the same with educations experience Doctoral to Bachelor's level.

There are some tasks that can only be performed by a BSP II, for example: completing functional assessments, creating positive behavioral support (PBS) plans, providing training to staff, evaluating/monitoring the effectiveness of the PBS plan, following up to observe progress/regression, and revising the PBS plan.

PART B – POTENTIAL BENEFIT #4: CRISIS INTERVENTION SERVICES

Appendix C-1/C-3: Crisis Intervention, Page 83-85:

Language has been added to include the IDT must hold a critical juncture meeting within the first 72 hours of the crisis.

Crisis services may be implemented immediately, for up to 72 hours, without prior authorization.

Crisis intervention services have been increased from 1,344 units/336 hours to 17,280 units/4,320 hours. Under the Purpose(s) of Amendment section Crisis Site Person Centered Support is noted as having an increase in service cap. This should state Crisis Intervention has an increase in service cap.

Includes the provision for the service to be provided via secure electronic means.

PART B – POTENTIAL BENEFIT #5: MEDLEY ADVOCATE AS AN IDENTIFIED IDT MEMBER
Appendix D-1: Participant-Centered Planning and Service Delivery/Service Plan Development, Page 166-168:
There is new language to identify the Medley Advocate as a required member of the IDT.

PART B – POTENTIAL BENEFIT #6: CASE MANAGEMENT FACE-TO-FACE VISITS
Appendix D-1: Service Plan Development Process, Page 166-168
New language is added stating, "The case manager is required to have a face-to-face contact with the member …. quarterly and electronically all remaining months (for members living in natural family settings) regardless of service delivery model to verify that services are being delivered in accordance with the IPP in a safe environment."

PART B – POTENTIAL BENEFIT #6: PARTICIPANT DIRECTION
Appendix E-1: Participant Direction of Services/Overview, Page 200-201:
The waiver application projects an increase in members engaging in Participant Directed Services. The current application identifies 2,352 members served through Participant Directed Services in Year 5. The waiver renewal application projects the following number of members participating in this service option:

- Year 1 – 2,352
- Year 2 – 3,259
- Years 3-5 – 3,520 for each year

This equates to the projection of an additional 1,168 people accessing Participant Directed Services.

PART C – AREAS THAT RAISE QUESTIONS

The Council has identified **six areas that raise questions** concerning the waiver application. These include:

1. Removal of Autism Spectrum Disorder Levels I and II as qualifying eligibility diagnoses.
2. Facility-Based Day Habilitation provided via secure electronic means.
3. The Participant-Directed Goods and Services exclusion list.
4. Licensed Group Home Person-Centered Support
5. Skilled Nursing Medication Administration Services
6. Base budget ranges

PART C – QUESTION #1: WAIVER ELIGIBILITY CRITERIA – AUTISM SPECTRUM DISORDER

Appendix B-1, Page 31-32 and Appendix B-6, Page 46:

How many members receiving I/DD Waiver services have a diagnosis of Level I or Level II ASD? How will this change affect them, and will they lose waiver services? What is the plan to inform members? If another qualifying condition is present with a diagnosis of Level I or Level II ASD will they automatically be deemed ineligible?

PART C – QUESTION #2: FACILITY-BASED DAY HABILITIATION

Appendix C-1/C-3: Service Specification: Facility-Based Day Habilitation, Page 62-64:

This service may be provided via secure electronic means. How can facility-based day habilitation services be provided via secured electronic means? The language in the renewal application does not specify how or in what context this is to be provided.

PART C – QUESTION #3: PARTICIPANT-DIRECTED GOODS AND SERVICES

Appendix C-1/C-3: Participant-Directed Goods and Services, Page 76-77:

Participant Directed Goods and Services – removed the specific exclusion list and indicated BMS will maintain a list. How will BMS develop and maintain the exclusion list in a transparent manner that involves stakeholder input? How will members and providers be made aware of the exclusion list?

PART C – QUESTION #4: LICENSED GROUP HOME PERSON-CENTERED SUPPORT

Appendix C-1/C-3: Licensed Group Home Person-Centered Support, Page 103-104:

This application continues to include the provision for, “Any person residing in a site serving more than four people must have a transition plan created to move to a site that services no more than four people within a three-year period.” This provision was included in the 2020 waiver application. There is no information on the BMS website for prior waiver applications to determine how many years this provision has been in place.

At a minimum it has been at least three to four years since this provision has been in place. How many licensed groups homes were there in 2020 and how many people are served? As of September 2023, how many licensed groups homes are in existence and how many people do they serve?

This there an anticipated timeframe when there will no longer be licensed residential waiver setting that serve more than four people.

PART C – QUESTION #5: SKILLED NURSING MEDICATION ADMINISTRATION
Appendix C-1/C-3: Limits on amount, frequency, or duration of service, Page 123-124:
The limit on amount, frequency, or duration of this service is stated as, "Events may not exceed 1,095 (an average of 3 medication passes per day) per IPP year. Only available to members living in a 24-hour setting. Events may not exceed 1,095 (an average of 3 medication passes per day) per IPP year. Only available to members living in a 24-hour setting. The amount of service is limited by the individuals assessed budget."

Is this new service intended to eliminate AMAPs from administering medications in 24-hour residential settings?

PART C – QUESTION #6: BASE BUDGET RANGES
Appendix C-4: Participant Services/Additional Limits on Amount of Waiver Services, Page 132-134:
Base budget ranges per setting and the maximum add-on to any member's base budget are not projected to change or increase from the previous 5-year waiver renewal application. This is a concern due to the increase in the cost of living, inflation and the direct support workforce crisis. Does the Bureau intend to raise waiver rates to assist service providers in offering more competitive wages?

If you have any questions, please contact me at (304) 558-0418 or tina.e.wiseman@wv.gov.

Sincerely,

Tina E. Wiseman
Executive Director

cc: Brandy Beery, Chairperson
DDC Staff