



COMMONWEALTH OF VIRGINIA  
*Virginia Board for People with Disabilities*

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TO: DDWaiver@dmas.virginia.gov  
Department of Medical Assistance Services

FROM: Teri Morgan

RE: Comment on Virginia's Renewal Application for its §1915(c) Home- and  
Community-Based Waiver for Individuals with Developmental Disabilities—  
Family and Individual Supports Waiver

I am writing to provide comments on behalf of the Virginia Board for People with Disabilities (the Board) regarding Virginia's *Request for a Renewal to a §1915(c) Home and Community-Based Services Waiver: Family and Individual Supports (FIS)*. The Board appreciates the opportunity to provide input.

The inclusion of telehealth/virtual supports as a mode of service delivery is positive progress that keeps pace with innovation and modernization in service delivery. The Board was a member of the two workgroups convened to expand access to telehealth/virtual supports and appreciates the Department of Medical Assistance Services for its work with stakeholders, providers, and others to facilitate implementation of recommendations from these workgroups.

The policy change to allow legally responsible persons (LRPs) to provide personal assistance services recognizes the valuable role of family caregivers in keeping families together and stable, leading to better overall health and well-being of families and children. The Board has heard firsthand from many families about the negative impact the pandemic had on the workforce that provides critical services that support children with disabilities and spouses with disabilities to remain in their communities with the families who love them.

The Board has also heard that workforce issues, including unreliability, the ongoing need to provide training for new personal assistants, and a “revolving door” of people in and out of their homes, were challenges that were prevalent before the pandemic, and now are worse. The flexibility of allowing LRPs to be the paid caregiver through Appendix K was a much-needed lifeline for many families. The General Assembly recognized this in 2022 through Budget amendment item 304#4h.

The Board offers the following comments and recommendations to improve the renewal application for the FIS waiver, including specific comments and recommendations regarding the allowance of LRPs to be paid providers of personal assistance services, organized by application section.

### ***Family and Individual Supports Waiver:***

#### **Brief Waiver Description**

- 1. The statement of goals and objectives should be revised to better reflect the purposes of the FIS waiver. The Board recommends that the goal and objectives of the Family and Individual Supports Waiver be revised to better reflect the tenants of the HCBS settings rule and national best practice.**

For example, the goal is *to provide a system of services and supports that empowers individuals with developmental disabilities to live healthy, productive, integrated lives in the community of their choice*. The objectives should be focused on achieving this goal, for example:

- Provide an array of services and supports to individuals with developmental disabilities that enable them to live meaningful lives in their communities of choice.
- Provide the supports and services necessary to strengthen families and enhance natural supports.
- Provide maximum opportunities for individuals with developmental disabilities to exercise independence, choice, and control over their own lives and their own services and supports.
- Increase access to waiver services for individuals and families to ensure that individuals with developmental disabilities can remain in the most integrated setting appropriate to their needs and desires.
- Develop a robust quality assurance system that ensures Medicaid-funded services and supports are person-centered, high quality, and cost-effective.

### **Appendix A: Waiver Administration and Operation**

2. **Quality Improvement: Administrative Authority of the Single State Medicaid Agency: The Board recommends a performance measure to strengthen oversight and facilitate transparency regarding the performance of contracted entities be added. For example,**

*Number and percent of deficiencies identified during the state monitoring activities that were appropriately and timely remediated by the contracted entity. N: Number of deficiencies identified during the states monitoring activities that were appropriately and timely remediated by the contracted entity D: Total number of deficiencies identified during the states monitoring activities*

The Quality Improvement strategy pertaining to administrative authority includes three performance measures. These performance measures cover all contracted entities, including DBHDS and the Fiscal/Employer Agent for fiscal management services for consumer-directed services as well as local/regional non-state public agencies that perform waiver operational and administrative functions, e.g., Community Services Boards. For the purpose of quality improvement, discovery, and remediation, adding a performance measure to monitor the identification and remediation of deficiencies would strengthen oversight of contracted entities.

### **Appendix B-3: Participant Access and Eligibility - Number of Individuals Served**

3. **“Waiver Movement and Emergencies” Section: The Board recommends that data related to past use of reserve slots be included in the application and an explanation of how this past use relates to the number of reserve slots contained in the application.**

The application states that the “Slots for facility downsizing are funded by the Virginia General Assembly according to the Commonwealth’s Settlement Agreement with the US Department of Justice.” While the Board understands that this explanation is technically accurate, in that the General Assembly ultimately determines the number of waiver slots available for individuals in the Commonwealth, this explanation does not discuss reserve slots for waiver movement and emergencies. Some discussion of historical rates of reserve slot usage would aid in determining whether the number of slots dedicated for this purpose in the future is appropriate and sufficient. Without this data, the reserve capacity contained in the application lacks sufficient context for meaningful evaluation.

### **Appendix B: Evaluation/Reevaluation of Level of Care - Quality Improvement: Level of Care**

4. **d. Level of Care Criteria: The Board recommends that the following statement be revised, “To ensure that Virginia’s home and community-based waiver programs serve only individuals who would otherwise be placed in an ICF/IID...” The eligibility requirement is that individuals meet the ICF/IID institutional level of care, thereby requiring an institutional level of care, not that they would otherwise be placed in an ICF/IID. It should**

**therefore read “To ensure that Virginia’s home and community-based waiver programs serve only individuals who require an ICF/IID institutional level of care...”**

In the Board’s 2022 Assessment of Access to Information for People with Disabilities and their Family Members, families report confusion about being asked if their family members will need to be placed in an institutional setting. There are opportunities to better communicate the Level of Care requirements in the waiver application and to family members. The current language is inconsistent with federal principles of person-centered, home and community-based systems of support. It is also incongruous that it is a key step in a process under a Department of Justice settlement agreement to promote community living outside of institutions. States such as Ohio, Pennsylvania and Maryland each require a clinician to document the need for an institutional level of care, but do not require families to explicitly state the need or eminent placement in an institutional setting.

**5. B-8: Access to Services by Limited English Proficiency Persons: **The Board recommends that this section be updated to reflect current information and practice.****

For example, the link to the VDH webpage for the application for birth certificates to verify identity and citizenship as part of the application for Medicaid does not work (<http://www.vdh.virginia.gov/vitalRecords/vtlapp.htm>); the VDH link to training and services available to providers serving Medicaid applicants and participants does not work (<http://www.vdh.virginia.gov/ohpp/CLASact/default.aspx>); the link to the DBHDS policies referenced does not work (<http://www.dbhds.virginia.gov/library/document-library/adm-sbpolicies1023.pdf>).

DMAS has a comprehensive Language and Disability Access Plan and resources to ensure access, such as a Civil Rights Coordinator. Less clear is the sufficiency of language and disability access plans and implementation by DBHDS and CSBs. This section in the waiver application references the DBHDS Office of Cultural Competency and the support and technical assistance provided to CSBs. Information about this office could not be located online. There is a DBHDS webpage titled Cultural and Linguistic Competence. However, this webpage references a Statewide Cultural and Linguistic Competence Advisory Committee (CLCAC) that does not appear to be active. Even less known, is the compliance of CSBs with the State Behavioral Health and Developmental Services Board policies. Per the January 2019 CMS Instructions, Technical Guide and Review Criteria for Medicaid 1915 (c) waivers, the review criteria for this section state the following: *“A variety of accommodations are described, both in conjunction with the waiver entrance process and for communicating with LEP persons on an ongoing basis (e.g., by providing for bilingual case managers).* The content of this section should be strengthened to, at a minimum, meet the review criteria requirements and intent, including for DBHDS and CSBs. DBHDS and CSBs compliance with the requirement for language access is questionable.

## **Appendix C: Participant Services**

6. **Personal Assistance Services, Legally Responsible Person (LRP): The Board recommends adding a consumer-directed option for LRPs while retaining the proposed agency-directed option.** The Board offers a number of recommendations with regard to LRPs which are divided below into two categories: agency-directed and consumer-directed.

### **Agency-Directed**

- a. **The Board recommends that a more detailed description of extraordinary care be included in the renewal application. The description should help better distinguish extraordinary from ordinary care.**

The current standard for extraordinary care in the application is that the care provided would be “above and beyond what the legally responsible individual is obligated to provide”. This standard on its own is ambiguous. Development of criteria and/or examples of what would qualify as “extraordinary” care could help to clarify. This may include a definition of “ordinary” care such as this example language provided by CMS: “care that is the typical responsibility of a LRP ordinarily provided to individuals, with or without a disability.” Or this CMS explanation: “By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.”

- b. **The Board recommends transparency regarding the additional cost to the Commonwealth of the change to a requirement of agency-directed for LRPs.**

It appears not necessarily cost effective to make the change to agency-directed for LRPs. The cost to the Commonwealth for agency-directed personal assistance is approximately \$6 per hour more than consumer-directed rates. In addition, many LRPs qualify for a tax exemption which results in currently no withholding for FICA. The FICA refunds the state receives through CD services would go away. The Board is concerned that the additional tax consequences of this change are not known and could add to the cost to the Commonwealth.

7. **Consumer-Directed: The Board recommends that a consumer-directed option for LRPs to provide personal assistance services be included in the FIS waiver renewal application.**

The Board worked with Applied Self Direction, experts in the area of self-directed, person-centered environments, to research current approaches in other states regarding LRPs being the paid support through consumer-directed services. We found that *Delaware, Florida, Kansas, Kentucky, Louisiana, Maryland, New Mexico, Pennsylvania, Rhode Island, and West Virginia* all report allowing LRPs to provide personal assistance through consumer direction. Here is an example of some of the language from Maryland's Family Supports Waiver (although their other DD waivers allow it as well):

The State makes payment to a legally responsible individual, who is appropriately qualified, for providing extraordinary care for the following services: Community Development Services or Personal Supports.

A legally responsible person may not be paid to provide these Waiver program services if it does not constitute extraordinary care as defined above.

## 2. CIRCUMSTANCES WHEN PAYMENT MAY BE MADE

Participant enrolled in the Self-Directed Services Delivery Model (as provided in Appendix E) or Traditional Service Delivery Model may use their legally responsible person to provide services in the following circumstances, as documented in the participant's Person-Centered Plan (PCP):

1. The proposed provider is the choice of the participant, which is supported by the team;
2. There is a lack of qualified providers to meet the participants needs;
3. When a relative or spouse is not also serving as the participant's Support Broker or designated representative directing services on behalf of the participant;
4. The legally responsible person provides no more than 40-hours per week of the service that the DDA approves the legally responsible person to provide; and
5. The legally responsible person has the unique ability to meet the needs of the participant (e.g. has special skills or training, like nursing license).

The CMS Guide: *Instructions, Technical Guide and Review Criteria for 1915(c) HCBS Waivers*, is a tool to aid states in designing their waivers. This Guide states that *"...providing payments to legally responsible individuals is a state option, not a federal requirement."* It does not exclude LRPs from providing personal assistance services through consumer direction.

The Board recognizes that there must be explicit rules and safeguards in place in order for LRPs to be the paid provider. For example, CMS requires the state to distinguish extraordinary care from ordinary care, include limitations on the amount of service for which payment can be made, and ensure that the provision of services by a LRP is in the best interest of the individual, as well as satisfy some additional protections. The recommendations below pertain to these requirements:

- a. **The Board recommends that a more detailed description of extraordinary care be included in the renewal application. The description should help better distinguish extraordinary from ordinary care.**

The current standard for extraordinary care in the application is that the care provided would be "above and beyond what the legally responsible individual is obligated to provide". This standard on its own is ambiguous. Development of criteria and/or examples of what would qualify as "extraordinary" care could help to clarify. This may

include a definition of “ordinary” care such as this example language provided by CMS: “care that is the typical responsibility of a LRP ordinarily provided to individuals, with or without a disability.” Or this description by CMS: “By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.”

- b. The Board recommends that objective written documentation be required accordingly: 1) when the parent of a minor child is the paid provider, 2) when a minor turns 18 years of age, 3) ongoing for an adult to receive services from a family member living under the same roof.**

DMAS regulations (12VAC30-122-120) currently require “objective, written documentation” for an adult to receive services from a family member living under the same roof. Similar documentation should be required for the following: 1) Objective written documentation for a LRP to be the paid provider for their minor child. This requirement would be consistent with the CMS extraordinary circumstance rules. 2) For some adults with disabilities, continued care from a parent or other loved one is their preferred option, but others may find it limiting and prefer a situation that would allow them more independence and autonomy. When a minor turns 18 years of age, objective written documentation must ensure that the person with a disability turning 18 is informed of all their options and freely chooses the person who is the paid provider. 3) The requirement for an adult to receive services from a family member living under the same roof is currently in place and should remain.

- 8. Personal Assistance Services:** In addition to the above regarding Personal Assistance Services:

- a. Personal Assistance Services, Service Definition: The Board recommends including information about nurse delegation (VA Code 18VAC90-19-240) in the service definition for this service.**

The delegation of nursing tasks and procedures is an option for people receiving personal assistance services under specific circumstances. Nurse delegation allows for greater autonomy and control by the individual receiving services and should be included in the service definition.

- b. Personal Assistance Services, Service Definition: The Board recommends that a statement be added to clarify that individuals who choose to receive services through the consumer-directed model may choose not to receive services facilitation.**

The services definition includes the following statement: *Individuals choosing to receive services through the consumer-directed model **may do so by choosing a services***



*facilitator to provide the training and guidance needed to be an employer.* It should be clarified that an individual can choose CD services and choose not to receive services facilitation. The option for a case manager, or another person of the individual's choosing, to serve in this role should be included in the waiver application.

- c. Personal Assistance Services, Consumer Directed Attendant Care: The Board recommends including information about nurse delegation (VA Code 18VAC90-19-240).

The delegation of nursing tasks and procedures is an option for people receiving CD personal assistance services under specific circumstances. Nurse delegation allows for greater autonomy and control by the individual receiving services and should be included here.

- d. Personal Assistance Services, Consumer Directed Attendant Care: The Board recommends amending the description of who may serve as an employer of record to include "or other chosen person" in order to maintain a consistent definition throughout the application.

9. Respite Services, Service Definition: The Board recommends including information about nurse delegation (VA Code 18VAC90-19-240).

As mentioned in the recommendations above, the delegation of nursing tasks and procedures is an option for people receiving CD respite services under specific circumstances. Nurse delegation allows for greater autonomy and control by the individual receiving services and should be included here.

10. Respite Services, Specify Applicable Limits on the Amount, Frequency or Duration of the Service: The Board recommends that clarification regarding the parameters of the 480-hour limit, e.g., per calendar year, state fiscal year, be included in the renewal application.

11. Respite Services, Specify Applicable Limits on the Amount, Frequency or Duration of the Service: The Board recommends clarification that if a legally responsible person is the provider of consumer-directed services, and there is an identified primary caregiver who is not the person providing services, respite services are available.

The limitation described in the waiver application is not accurate: *"Individuals who receive personal care from a legally responsible individual shall not be authorized for the respite service, as the legally responsible individual, as primary caregiver, is paid."*

An individual can have a legally responsible person as a provider of consumer-directed services, and also have an identified primary caregiver in need of respite services. This should be clarified in the application.



- 12. Respite Services, Specify Applicable Limits on the Amount, Frequency or Duration of the Service: The Board recommends that Legal Guardian be checked as an authorized provider of respite services.**

We believe this omission was an oversight.

- 13. Companion Services, Specify Applicable Limits on the Amount, Frequency or Duration of the Service: The Board recommends that Legal Guardian be checked as an authorized provider of companion services.**

We believe this omission was an oversight.

- 14. Services Facilitation: The Board recommends re-examining the role of the consumer-directed services facilitator to eliminate unnecessary duplication of functions and more clearly delineate the roles of services facilitators, support coordinators, and CCC Plus care coordinators.**

Service facilitators, support coordinators, and CCC Plus care coordinators are all responsible for monitoring services. This can result in duplication of effort, diffusion of responsibility, confusion, and reduced individual ownership of responsibility. It can also unduly burden individuals who must accommodate multiple home visits and assessments.

When various parties have overlapping roles, DMAS should either distinguish how each party's contribution to the overall role differs from the others' contributions or, if the contributions do not differ, consolidate the role under fewer parties. The cost of this service should be analyzed in relation to the benefit achieved for the funding agency and the consumer.

- 15. Assistive Technology, Service Definition, Specify Applicable Limits on the Amount, Frequency or Duration of this Service: The Board recommends that DMAS clarify that if assistive technology is denied under EPSDT, in some circumstances, the technology can be assessed under DD waiver Assistive Technology rules.**

The Board was a member of the HB 990 workgroup which required DMAS to continue to study and develop recommendations for the permanent use of virtual supports and increase access to virtual supports. EPSDT was discussed extensively by this workgroup. In particular, denials for assistive technology (AT) under EPSDT rules. DMAS reported confirmation from CMS that if AT is denied under EPSDT rules, the AT can be reviewed under waiver rules to determine if the AT is allowable. This should be included in the application.

- 16. Assistive Technology: Service Definition: The Board recommends clarification in the AT service definition that criteria for AT includes the ability to *“actively participate in other waiver services that are part of their plan for supports.”* In addition, expand the service**

**definition to also focus on functional abilities versus just “remedial or direct medical benefit”.**

The CMS definition focuses on functional abilities and not only medical needs, which would include the ability to actively participate in other waiver services that are part of a person’s plan for supports.

**17. Peer Mentor Supports: The Board recommends clarifying what “Prior to accessing funding for this waiver service, all other available and appropriate funding sources must be explored and exhausted” means in the context of eligibility for this service.**

**18. Peer Mentor Supports: The Board recommends clarifying what it means to have “lived independently in the community” as this phrase is used in the Waiver application to describe the individuals who may provide peer mentor supports.**

The application states: *“Peer Mentor Supports are provided by an individual with a developmental disability who has lived independently in the community for at least one year and is or has been a recipient of services, including but not limited to, publicly-funded housing, Medicaid waiver services, work incentives, and supported employment.”* It is unclear what it means to have “lived independently in the community” for the purposes of determining one’s qualifications to provide peer mentor supports. The Board is concerned that the phrase is susceptible to interpretations that would exclude a number of people with developmental disabilities who would be well-suited to delivering the allowable activities defined in the application. The phrase could be interpreted, for instance, to mean that an individual must live in his or her own apartment or home, which could exclude individuals in other types of residential settings, such as supported living, who could prove very capable of acting as peer mentors. The Board recommends that DMAS reconsider and/or clarify the standard.

**19. Environmental Modifications, Service Specification, Service Definition : The Board recommends that DMAS allow authorization for environmental modifications needed to transition from an institutional setting to the community up to 180 consecutive days in advance of the community transition.**

The inability to access environmental modifications prior to transitioning from an institutional setting to a community setting has been a long-standing barrier for many people. CMS allows the needed environmental modification to be authorized and begun while the individual is still in the institution. This allowance is described on page 174 of the CMS, “Instructions, Technical Guide and Review Criteria” for 1915(c) waivers.

### **Appendix D: Participant-Centered Planning and Service Delivery - Quality Improvement: Service Plan**

20. “Sub-assurance: Service plans address all participants assessed needs (including health and safety risk factors) and personal goals, either by provision of waiver services or through other means” Section: **The Board recommends adding performance measures that speak to the satisfaction of the individual and/or their chosen team members with their service plan.**

The proposed performance measures focus on whether the service plans address individuals’ assessed risks, but do not appear to speak to whether the service plans address participants’ personal goals. Absent standard documentation of individuals’ goals against which to compare the service plans, one source of relevant information is the individuals’ and/or chosen team members’ satisfaction level with the service plans. The waiver application indicates that some form of satisfaction information is obtained during and following service plan development. According to the “Service Plan Development Process” section under Appendix D-1, “An evaluation of how the plan achieves the desired outcomes, from the individual’s and responsible partners’ perspectives, is completed prior to final agreements.” The waiver application should include a performance measure that speaks to this information collected regarding satisfaction with the service plan.

### **Appendix E: Participant Direction of Services**

21. “Election of Participant Direction” Specify the Criteria: **The Board recommends changing the first sentence from “Individuals assessed as having an intellectual disability that may limit or prevent...” to “Individuals assessed as having a developmental disability that may limit or prevent...”**

### **Appendix F-1: Participant Rights - Opportunity to Request a Fair Hearing**

22. “Procedures for Offering Opportunity to Request a Fair Hearing” Section: **The Board recommends reconsideration of two of the items (#6 and #7) in the exception list for advance notification of adverse action.**

With respect to #6, the *individual's physician prescribes a change in the level of care*, the individual may not agree with the recommendation of his physician and may seek a second opinion on the appropriateness of care or services. The 10-day advance notice should be afforded to individuals so that they have an opportunity to seek additional information or clarification from their or another physician prior to service termination.

With respect to #7. *When the individual's request for admission into a Medicaid-covered service or when the individual's request for an increase in a Medicaid-covered service is denied or not acted upon promptly for any reason, i.e., diagnostic or functional eligibility,*

*funding, no provider*, there is also no reason that advance notice should not be provided to the individual so that she can seek assistance, particularly with respect to locating a provider.

Unless the situation is an emergency, advance notice of adverse action should always be provided.

### **Appendix G-1: Response to Critical Events or Incidents**

**23. “State Critical Event or Incident Reporting Requirements” Section: The Board recommends updating the language regarding required reporting of deaths and serious injuries to account for new requirements added to 12 VAC 35-105-160.**

Reporting requirements for DBHDS-licensed providers in 12 VAC 35-105-160 have changed. Previously, providers were required to collect, maintain, and report each death or serious injury. Now, providers are required to collect, maintain, and report Levels II and III serious incidents. Providers are also required to collect, maintain, and review at least quarterly (but not report) all Level I serious incidents. Definitions of Levels I, II, and III serious incidents should be included in the application. References to “serious injuries or deaths” throughout Appendix G should be changed to “serious incidents” for consistency.

**24. “State Critical Event or Incident Reporting Requirements” and “Responsibility for Review of and Response to Critical Events or Incidents” Sections: The Board recommends adding references, where appropriate, to the roles of the state’s protection and advocacy entity.**

The state’s protection and advocacy entity receive and review complaints, which may or may not involve critical incidents pertaining to waiver recipients. The *Code of Virginia* §37.2-709 also requires reporting of all critical incidents and deaths in facilities and in the community to the state’s protection and advocacy entity, as well as allegations of abuse or neglect that are required to be reported pursuant to regulations adopted by the Board pursuant to Chapter 4 (§ 37.2-400 et seq.). The protection and advocacy entity, along with various other entities including the State Long-Term Care Ombudsman, are also entitled to receive Adult Protective Services information per 22 VAC 30-100-50.

**25. C. Participant Training and Education: The Board recommends that DMAS remove the reference to the Guide to Long Term Care Services in Virginia contained on the Virginia Health Information website from the application.**

The guide referenced pertains to nursing facilities, assisted living facilities, adult day care centers, etc. It does not pertain the HCBS waiver services and does not address the reporting of abuse, neglect and exploitation as inferred in the waiver application.