



September 25, 2023

Erica Ross-Skianes
Program Planner III
Office of Client and Legal Services
New Hampshire Department of Health and Human Services
105 Pleasant Street
Concord, NH 03301

Via Email: Erica.M.Ross-Skianes@dhhs.nh.gov

Re: PART He-M 517- MEDICAID-COVERED HOME AND COMMUNITY-BASED CARE SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES AND ACQUIRED BRAIN DISORDERS

Dear Ms. Ross-Skianes,

Thank you for the opportunity to provide comments on the He-M 517 rules during the informal comment process. The Council received the draft rule for informal comment on August 18, 2023 and could not complete this draft until the next scheduled Quality Council meeting on September 20, 2023. We hope that you will still consider this feedback in the informal drafting process.

Overview

In addition to the specific comments on He-M 517 below, the Quality Council wants to encourage BDS to provide additional support to people with disabilities and families to understand the regulations and regulatory process. Simple changes like adding the title/topic when a rule references another rule would help with ease of understanding.

We also encourage BDS to develop or support the development of a guide to the regulatory process in plain language to be shared widely with people with disabilities and their families. We are pleased that BDS is developing a process to develop plain language versions of rules and look forward to learning more as the process develops.

It is critical that these rules and all rules governing developmental services consider the needs of all individuals receiving services including people with low and high support needs, to ensure that people with the highest needs or unique needs are able to access supports. Many community-based services including community participation services are not universally designed.

The Quality Council appreciates the removal references to he/him and she/her. Rules should reflect gender neutral language.

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Disability Rights Center - NH

Isadora Rodriguez-
Legendre, Vice Chair
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Developmental Disabilities*

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Community Support Network, Inc

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People First of New Hampshire

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*NH Council on
Developmental Disabilities*

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Brain Injury Association of NH

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Area Agency Board Member

Lisa Steadman
Family Support Council Member

Mary St. Jacques
Institute on Disability

Sarah Tollefsen
ABLE NH

He-M 517.02 Definitions

(i) *“Community integration” means:*

(1) *Participation in a wide variety of experiences in settings that are available to and used by the general public;*

(2) *Participation in natural relationships with one’s family, friends, neighbors, and co-workers; and*

(3) *Expansion of one’s personal network of friends to include individuals who do not have disabilities.*

The Council encourages the Bureau to explore alternative definitions for community integration. For example, this definition from Utah more closely reflects the Council’s understanding of community integration.

“Community integration is the opportunity for individuals with disabilities to live in the community and be valued for their uniqueness and abilities to the same extent as others without disabilities. Community integration means actively working to not only bring individuals into the community, but also ensuring that they are able to contribute to the development of the community and feel like they are an integral part of it.”

<https://medicaid.utah.gov/Documents/pdfs/ltc/hcbstransition/Files/Community%20Inclusion%20and%20Integration%20Flyer.pdf>

(s) *“Natural supports” means people such as family, relatives, friends, neighbors, and clergy, and social groups such as religious organizations, co-workers, and social clubs, available to provide comfort and help as part of everyday living as well as during critical events.*

The Council encourages the Bureau to examine this definition more closely. In our understanding, natural supports are typically provided without compensation and this is not reflected in the definition. Also, natural supports should provide support to the person with disabilities. This may or may not include comfort or help. Finally, the support to be provided and supporter must be chosen by the person with disabilities. Not everyone who is available will be an appropriate supporter.

(z) *“Representative” means:*

(1) *The parent or guardian of an individual under the age of 18;*

(2) *The legal guardian of an individual 18 or over; or*

(3) *A person who has power of attorney for the individual.*

The Council recommends that this rule incorporates the assistance of a supporter for a person with developmental disabilities wherever necessary. In a supported decision-making agreement, the person with disabilities retains the authority to make their own decisions but can request and receive assistance from a supporter. We recommend that it be added to the definitions and to the following sections of the waiver as appropriate.

The Council recommends adding definitions of person center plan and person-centered service plan in this rule or one of the other DD rules. These definitions should reflect the concepts from the Council's letter on person centered planning sent on July 6, 2023 and available at https://www.nhqualitycouncil.org/files/ugd/78293e_837cdb5428b145e1a5e8371242593c0d.pdf.

The Council recommends standardizing definitions over all the DD rules whenever possible and linking to one another. This will minimize confusion.

He-M 517.03 Eligibility.

(d) To request a redetermination of the level of care in 517.03(a)(4) above, a "NH bureau of developmental services functional screen for waiver services" electronic form shall be submitted via NH Easy (add link) not less than 30 days but not more than 45 days prior to expiration of the current level of care determination.

The 15-day window for the submission of this form seems very narrow. The Council recommends that BDS reconsider this to allow for additional flexibility in the submission of this form.

He-M 517.04 Provider and Provider Agency Participation.

(b) An OHCDs or provider agency shall allow the department or area agency to examine its service and financial records at any time for the purposes of audit or review.

The Council recommends that this provision be rewritten to clarify which organizations can access records and for what purpose.

He-M 517.05 Covered Services.

(a) All home and community-based waiver services provided shall be specifically tailored to, and provided in accordance with, the individual's needs, interests, competencies, and lifestyle as described in the individual's service agreement.

The Council recommends that this provision be rewritten to include a reference to an individual's person-centered plan if applicable. In addition, we recommend that the sentence be divided or otherwise rewritten in plain language.

(b) Services provided pursuant to He-M 517 shall be:

(1) Designed to maintain and enhance each individual's natural supports;

The Council is concerned about this language. Natural supports are very important to people with developmental disabilities, but our current system relies too much on natural supports (families) when paid supports are not available due to workforce shortages or adequate rates. We are concerned that this is the first item on the list and could be read to place an unfair burden on families, as in the current system.

(2) Responsive to the individual's changing needs and choices within the limitations of federal and state laws and rules;

(3) Provided only after the informed consent of the individual and/or their guardian or representative if applicable;

The Council believes that /or in the sentence above should be included. Individuals with disabilities should provide informed consent to their services whenever possible.

(4) Free from conflict in accordance with He-M 503 or He-M 522;

(5) Delivered by any willing and qualified provider agency or provider that is freely chosen by the individual or individual's guardian or representative; and

As noted above, the provider should be chosen by the individual. The Council believes that "or" should be replaced with "and".

(d) Service coordination services shall:

(1) Be provided pursuant to He-M 503 or He-M 522;

(2) Include the following:

(d:2 a) Coordination and facilitation to assist individuals in gaining access to needed services and resources, as well as needed medical, social, educational, and other services, regardless of funding source, as of all supports and services delineated in the service agreement, including;

1. System navigation including identifying, providing information about, and assisting families to access available services as well as community resources, including but not limited to;

2. Person-centered service planning including coordination and facilitation of services and the development of a service agreement pursuant to He-M 503.09 and 503.10 or 522.10 522.11;

3. Monitoring and ongoing review of services and individual outcomes, in accordance with He-M 503.10 or 522.11 to include assessing and reassessing service needs, goals and outcomes;

4. Monitoring of services for quality in accordance with 503.10 or 522.11;

The Council believes that there is still some confusion regarding the role of the service coordinator, area agency and bureau to measure the quality of services and take action.

5. Monitoring to ensure health and welfare in accordance with 503.10 or 522.11; and

6. Assistance in identifying available provider agencies and providers;

The Council recommends adding "Coordination of the development of the person centered plan" to this list of responsibilities.

c. 24/7 access for outreach regarding individuals supported

The Council recommends that this section include the specific language regarding 24/7 access for service coordinators or references the provision in He-M 504.

(e) Residential Habilitation services shall :

- (1) Be provided pursuant to He-M 1001, He-M 525, or He-M 521, as applicable;
- (2) Include individually tailored supports to assist with the acquisition, retention, or improvement of community living skills including but not limited to:
 - a. Meal preparation;
 - b. Eating;
 - c. Bathing;
 - d. Dressing;
 - e. Personal hygiene;
 - f. Medication management;
 - g. Community inclusion;
 - h. Transportation;
 - i. Social and leisure skills; and

The Council recommends adding a reference to hobbies and fun activities to this provision.

j. Adaptive skill development.

The Council is not sure what this is and recommends revising or adding a definition and adding examples like budgeting, time management, self-advocacy.

In addition, the following skills should be added to this list:

- organizing/domestic skills/housekeeping/keeping personal space clean
- self determination/independence

(3) Include assistance to the individual to enable them to reside in the least restrictive setting most appropriate to their needs;

(4) Be provided in the home or outside of the home;

(5) Be reimbursed at a daily rate;

(6) Except as allowed by (7) below, all community residences shall be certified pursuant to He-M 1001. Community residences that serve 4 or more people shall also be licensed by the bureau of health facilities administration in accordance with RSA 151:2, I, (e) and He-P 814;

(7) A residence funded under the home and community-based care waiver that provides services to persons with acquired brain disorders and is licensed as a supported residential care facility or a residential treatment and rehabilitation facility under RSA 151:2, I, (e) shall not be required to be certified as a community residence pursuant to He-M 1001;

(8) Residential habilitation services described in He-M 521.03 and provided in the family home of an individual who is 18 years of age or older shall be certified pursuant to He-M 521.09; and

(9) Services provided through a participant directed and managed services method of delivery shall be certified pursuant to He-M 525.

While this might not be the appropriate location, the Quality Council recommends that the Bureau outlines expectations for the closure of residential facilities in rule including timelines for voluntary closure whenever possible to ensure smooth transitions for residents but also make sure that providers are willing to accept residents who may be more challenging to serve. The Council recommends additional conversations with people with disabilities, family members, providers, case managers and area agencies as these standards are developed.

(f) Community participation services shall:

(1) Be provided in accordance with He-M 507.04;

(2) Include the following as required outlined in by the individual's service agreement:

a. Instruction and assistance to learn, attain, improve, or maintain:

1. Social and safety skills in different community settings;

2. Decision-making regarding choice of and participation in community activities;

3. Life skills as applied to community-based activities, such as purchasing items and managing personal funds;

4. Good nutrition and healthy lifestyle;

The Council recommends adding "communication skills" to this list.

(g) Supported Employment services shall:

(1) Be provided in accordance with He-M 518;

(2) Be available to any individual who:

a. Has a goal or desired outcome related to an employment goal; and

b. Is not authorized and funded by the NH department' of education's bureau of vocational rehabilitation for the same supported employment service;

(3) Consist of assistance provided to individuals to:

a. Improve or maintain their skills in employment activities; or

b. Enhance their social and personal development or well-being within the context of vocational goals;

(4) Include referral, evaluation, and consultation for adaptive equipment, environmental modifications, communications technology or other forms of assistive technology, and educational opportunities related to the individual's employment services and goals;

(5) When combined with another employment service, transportation and training in accessing transportation, as appropriate, to and from work; and

(6) Be reimbursed at a quarter hour rate.

The Council recommends advocacy to improve the quality of vocational rehabilitation services in the state. Vocational rehabilitation services are generally matched by federal funds at a much higher rate (approximately 79% compared to 50%) than Medicaid expenditures. It is important that supported employment services in the DD waiver supplement and not supplant vocational rehabilitation services. The Council recommends further discussion about improving supported employment services for people with developmental disabilities.

(h) Respite care services shall:

(1) Be provided pursuant to He-M 513;

(2) Consist of the provision of short-term assistance and care for individuals unable to care for themselves because of the absence or need for relief of the family who lives with and normally provide care for the individual;

(3) Be provided in or out of an individual's home;

(4) Not exceed 20% of an individual's total funding for services when provided through a participant directed and managed program as outlined in 517.07 below and He-M 525;

(5) Be authorized by the bureau in excess of the limitation in (4) above upon written request which shall include documentation supporting the need and the correlation of the request to the individual's service agreement; and

(6) Be reimbursed at a quarter hour rate.

The Council is concerned about how respite services are provided. Some concerns include the 20% cap for PDMS families, reporting requirements, TB test requirements. We recommend further discussion as the new waiver is developed, including discussions with people who are using this service. We need a system that is flexible and able to meet a variety of needs.

(i) Environmental and vehicle modification services shall:

(1) Include modifications or adaptations to the individual's home environment including:

- a. *Installation of ramps;*
- b. *Installation of grab bars;*
- c. *Widening of doorways to accommodate the participant's wheelchair or other mobility access equipment; and*
- d. *Other adaptations authorized by the bureau that are necessary to ensure the health and safety of the individual or that are needed to accommodate the medical equipment and supplies that are necessary for the welfare of the individual.*

The Council recommends adding "ongoing service, maintenance and repairs of home and vehicle modifications" to this list. Many modifications like wheelchair lifts, adaptive vehicle controls and others require ongoing maintenance to be used safely. Ongoing maintenance may actually cost less over the long term.

(2) Include modifications or adaptations to the vehicle used by the individual in order to enable them him or her to:

- a. *Travel in greater safety;*
- b. *Access the community; and*
- c. *Carry out activities of daily living;*

The Council recommends adding additional criteria to allow access to these services with approval from the Bureau even if the proposed service does not meet one of these criteria.

(k) Community support services shall:

(1) Be available for an individual who has developed, or is trying to develop, skills to live independently within the community;

The Council believes that maintaining or sustaining skills to live independently is also important and should be allowed under this service.

(2) Consist of assistance, excluding room and board, provided to an individual to:

- a. *Improve or maintain their skills in basic daily living and community integration; and*
- b. *Enhance their his or her personal development and well-being; and*

(3) Not exceed 30 hours per week.

(4) Be provided for up to 24 consecutive months while an individual is residing with their family;

(5) Be authorized by the bureau in excess of the limitation in (3) and (4) above upon written request which shall include documentation supporting the need and the correlation of the request to the individual's service agreement; and

(36) *Be reimbursed at a quarter hour rate.*

(l) Assistive technology shall:

(1) Include an item, piece of equipment, certification and training of service animal, or product system, used to increase, maintain, or improve functional capabilities of an individual, including, but not limited to, the following:

a. Devices, controls, or appliances, specified in the individual service agreement that enable the individual to increase their ability to perform activities of daily living, or perceive, control, or communicate with the environment in which they live;;

b. The evaluation of the assistive technology needs of an individual, including a functional evaluation of the impact of the provision of appropriate assistive technology and appropriate services to the individual;

c. Purchasing, leasing, or otherwise providing for the acquisition of assistive technology or devices;

d. Selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices;

e. Coordination and use of necessary therapies, interventions, or services associated with other services in the service agreement;

f. Training or technical assistance for the individual or the individual's family members, guardians, advocates, or authorized representatives;

g. Training or technical assistance for professional or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of an individual; and

h. Training and certification of a service animal, defined in federal regulations implementing the Americans with Disabilities Act, 28 C.F.R. § 36.104 as "service animal means any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability. Other species of animals, whether wild or domestic, trained or untrained, are not service animals for the purposes of this definition. The work or tasks performed by a service animal must be directly related to the individual's disability."

The Council encourages the Bureau to explore the use of miniature horses as service animals as outlined in 28 CFR 36:302. The Council also encourages the Bureau to allow for funding for ongoing expenses for service animals including veterinary services, pet insurance, food and additional training. These ongoing expenses should not be covered by the cap or there must be an exceptions process if necessary.

(n) Community Integration Services shall:

(1) Be services designed to support and enhance an individual's level of functioning, independence and life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by a disability shall include, but not be limited to the following:

The Council believes that this sentence is confusing and does not reflect plain language. In addition, the Council recommends replacing "and" with "or" to read "support or enhance". Community integration services may not always enhance functioning.

a. Water safety training;

b. Community based camperships; and

c. A pass or membership for admission to community based activities only when needed to address assessed needs.

(2) When including community based activity passes, be purchased as day passes or monthly passes, whichever is the most cost effective;

(3) Not exceed \$ 8,000 annually ;

(4) Be authorized by the bureau in excess of the limitation in (3) above upon written request which shall include documentation supporting the need and the correlation of the request to the individual's service agreement; and

(5) Require a licensed healthcare practitioner's recommendation when any single community integration service, other than a campership, is over \$2,000.

The Council has had a number of discussions about the importance of community integration services for people with developmental disabilities and will be considering a separate letter on this service at the September 20, 2023, Council meeting.

In addition, the Council is concerned if these services can only be paid via reimbursement as this may limit access to these funds for people with limited resources. Some people who need an ongoing service may not have the funds to pay for the first month or two while the Medicaid payments are being processed. We recommend that this be handled like individual goods and services.

(o) Individual goods and services shall:

(1) Include equipment or supplies that address an identified need in the service agreement, and meet at least one of the following requirements:

a. The good or service decreases the need for other Medicaid services;

b. The good or service promotes inclusion in the community; or

c. The good or service increases the individual's safety in the home environment.

(2) Include payment through the home and community based services waiver if:

a. The individual and their family do not have the funds to purchase the item or service;

The Council is very concerned about this requirement. First, it is not reasonable to expect the family of an adult with developmental disabilities to purchase individual goods and services that are required for developmental disabilities services. Second, how is the person with developmental disabilities expected to demonstrate that they do not have funds to purchase the needed good or service. To qualify for the DD waiver, participants must be eligible for Medicaid. If this is a federal requirement, the Council recommends additional work on how this is implemented in New Hampshire.

b. The item or service is not available through other sources.

The Council recommends that “available” be replaced by “covered”.

(3) Not exceed \$1,500 annually;

(4) Be authorized by the bureau in excess of the limitation in (4) above upon written request which shall include documentation supporting the need and the correlation of the request to the individual's service agreement;

(5) Have an anticipated finite period of time to be utilized; and

(6) Include a determination on the frequency of purchase of individual goods and services in accordance with the documented continued need of the item and the ability of the item to continue to meet that need.

(p) Non-medical transportation shall:

(1) Be services designed specifically to improve the individual's and the caregiver's ability to access community activities within their own community in response to needs identified through the individual's service agreement, including, but not limited to:

a. Orientation service using other services or supports for safe movement from one place to another;

b. Travel training such as supporting the individual and family in learning how to access and use informal and public transport for independence and community integration;

c. Transportation service provided by different modalities, including public and community transportation, taxi services, transportation specific to prepaid transportation cards, mileage reimbursement, volunteer transportation, and non-traditional transportation providers; and

d. Prepaid transportation vouchers and cards.

(2) Payment for non-medical transportation shall be limited to:

a. \$5,000 annually; or

b. \$10,000 annually for individual's who require specialized transportation such as a vehicle that:

- 1. Can accommodate a wheelchair or similar;*
- 2. Has lift capabilities; or*
- 3. Allows for the individual to not be within reach of the driver.*

(3) Be authorized by the bureau in excess of the limitations in (2) (a)-(b) above upon written request which shall include documentation supporting the need and the correlation of the request to the individual's service agreement;

(4) Be limited to transportation needed:

- a. To access a waiver service that is included in the individual's service agreement; or*
- b. To access other activities and resources identified in the individual's service agreement.*

(5) Not be available to individuals under the age of 16 for public transportation expenses.

The Council recommends that the Bureau explore support for providers to purchase vehicles to provide this service. In addition, the Council hopes that this service will be available throughout the state before and after traditional business hours and on the weekend. Finally, the Council recommends consideration of the purchase of gift cards for Uber, Lyft, taxi and other on demand transportation services as the individual must pay for the trip when it is provided. These companies are not arranged to accept delayed payment via Medicaid. As noted above, this may restrict individuals with limited resources from accessing this service.

(q) Personal emergency response services (PERS) shall:

(1) Consist of smart technology devices that enable individuals to summon help in an emergency including but not limited to:

- a. Wearable or portable devices that allow for safe mobility;*
- b. Response systems that are connected to the individual's telephone and programmed to signal a response center when activated;*
- c. Staffed and monitored response systems that operate 24 hours a day, seven days a week;*
- d. Any device that informs of elopement; and*
- e. Monthly expenses that are affiliated with maintenance contracts or agreements to maintain the operations of the device or item.*

(2) Include non-smart technology items, such as seatbelt release covers, ID bracelets, and GPS devices;

(3) Not exceed \$2,000 annually;

The Council supports the addition of this service.

(r) Wellness coaching shall:

(1) Include planning, directing, coaching, and mentoring individuals with disabilities in community based, inclusive exercise activities in accordance with the recommendations of a licensed recreational therapist or a certified personal trainer;

(2) Include specific goals in the individual's service agreement which are developed by a wellness coach, including activities that are carried over into the individual's home and community;

(3) Consist of demonstration by a wellness coach on exercise techniques and form to include observation of individuals and explanation to them of corrective measures necessary to improve their skills;

The Council is concerned that this restriction regarding exercise techniques is too limiting. Wellness coaching could and should also cover cooking classes, meditation and other activities not related to exercise. In addition, this should cover yoga classes, dance classes and other community based group activities that promote wellness.

(4) Include collaboration between a wellness coach and the individual, their family and other caregivers, and with other health and wellness professionals as needed;

(5) Not exceed \$5,000 hours annually; and

(6) Be authorized by the bureau for hours in excess of the limitation in (5) above by written request, which shall include the recommendation of a licensed professional and documentation supporting the need and the correlation of the request to the individual's service agreement.

The Council encourages the Bureau to explore how this is being provided, including the burden on personal trainers, instructors and others to navigate the Medicaid system for payments for a class. We do not want the providers to face hurdles which would discourage them from including people with developmental disabilities.

In addition, it's important that adaptive sports are included as are community activities available to the general public for a fee.

Finally, the Council encourages further discussion with service coordinators about the availability of this service as it seems like there is much confusion, particularly when wellness coaching is an option to pay for services previously funded under community integration.

He-M 517.06 Acute and Remote Setting Services.

(a) Upon request, services in (d) and (e) below shall be provided in an acute care hospital when each service is:

- (1) Identified in an individual's service agreement;*
- (2) Provided to meet needs of the individual that are not met through the provision of hospital services;*
- (3) Not a substitute for services that the hospital is obligated to provide through its conditions of participation or under federal or state law, or under another applicable requirement; and*

It is important to make sure providers understand when it is appropriate that acute services are provided in a hospital and that the hospital meets its obligations to provide services to patients.

- (4) Designed to ensure smooth transitions between acute care settings and home and community-based settings, and to preserve the individual's functional abilities.*

(b) If services in (d) are provided pursuant to (c) below, then those services shall be reviewed by the team at the quarterly meeting to ensure this method of service delivery continues to meet the individual's needs.

(c) Upon request, services in (d) below shall be provided remotely under the following conditions:

- (1) This method of service delivery meets the assessed needs of the individual;*
- (2) The individual, guardian, or representative chose this method of service delivery;*
- (3) This method of service delivery is reviewed by the team at the quarterly meeting to ensure that it continues to meet the individual's needs; and*
- (4) The chosen method of service delivery is in compliance with Health Insurance Portability and Accountability Act requirements.*

The Council believes that personal health information as defined in HIPAA is protected. However, some waiver services like personal training, coaching or others may not require the sharing of personal information as defined in HIPAA. These providers should not be expected to invest in a HIPAA compliant service delivery system as this can only discourage them from providing the service.

(d) Services that may be provided through a remote method of service delivery pursuant to (c) above shall include:

- (1) Community participation services;*
- (2) Residential habilitation;*
- (3) Service coordination, except home visits pursuant to He-M 503 or He-M 522 for residential services;*
- (4) Supported employment;*
- (5) Assistive technology;*

- (6) *Community integration services;*
- (7) *Community support services;*
- (8) *Crisis response services;*
- (9) *Individual goods and services;*
- (10) *Specialty services; and*
- (11) *Wellness coaching.*

(e) *Services that may be provided in an acute care hospital pursuant to (a) above shall include:*

The Council recommends that the Bureau take steps to make sure families are not caught in the middle of billing disputes between hospitals and waiver services providers. This can cause unnecessary delays in the provision of services.

- (1) *Community participation services;*
- (2) *Residential habilitation;*
- (3) *Respite;*
- (4) *Service coordination;*
- (5) *Supported employment;*
- (6) *Assistive technology;*
- (7) *Community support services;*
- (8) *Crisis response services;*
- (9) *Environmental and vehicle modification services;*
- (10) *Individual goods and services;*
- (11) *Personal emergency response services;*
- (12) *Removable prosthodontic services;*
- (13) *Specialty services; and*
- (14) *Wellness coaching.*

He-M 517.07 Out of State Service Provision

(a) *Services outlined in (c) below shall be provided outside of New Hampshire as follows:*

- (1) When the only safe and accessible setting is outside of New Hampshire;*
 - (2) Only until a setting is available in New Hampshire;*
 - (3) The services are approved by the bureau in accordance with (b) below; and*
 - (4) The services are outlined in the individual's service agreement to reflect the amount, scope, duration and frequency of the service and the oversight and monitoring of the service agreement.*
- (b) Out-of-state service provision shall be requested via written request to the bureau which shall include:*
- (1). A transition plan with a timeframe for return to New Hampshire;*
 - (2) Verification that the provider agency meets criteria in accordance with He-M 504, He-M 506, He-M 507, and He-M 518, as applicable;*
 - (3) Demonstration that the provider is in good standing through licensing or certification reports from the previous 5 years, or the maximum number available for providers established within the previous 5 years, from any in-state or out-of-state entity, including deficiency reports and compliance records;*
 - (4) A plan that will be articulated in the service agreement to demonstrate how an individual will access acute care as well as ongoing medical and clinical needs that are not covered by the home and community based waiver; and*
 - (5) A plan that will be articulated in the service agreement for oversight and monitoring of the service plan in accordance with He-M 503 or He-M 522.*
- (c) Services that may be provided out-of-state pursuant to (a)-(b) shall include:*
- (1) Community participation services;*
 - (2) Residential habilitation;*
 - (3) Supported employment;*
 - (4) Assistive technology;*
 - (5) Community integration services;*
 - (6) Community support services;*
 - (7) Crisis response services;*
 - (8) Environmental and vehicle modification services;*
 - (9) Individual goods and services;*
 - (10) Non-medical transportation;*

- (11) *Personal emergency response services;*
- (12) *Removable prosthodontic services;*
- (13) *Specialty services; and*
- (14) *Wellness coaching.*

The Council recommends that the Bureau add an exception for people living in border cities to access out of state services. Sometimes, these are the closest available services.

(n)He-M 517.08 Participant Directed and Managed Services shall:

(a) Services that are accessed through the participant directed and managed method of service delivery shall:

- (1) Be provided pursuant to He-M 525;*
- (2) Be available for individuals and their families in order to improve or maintain each individual's health and their his or her experiences and opportunities in work and community life;*
- (3) Consist of assistance and resources within a flexible process that allows the family and individual to control, to the extent desired, the service provision, including, for each service:*
 - a. The type;*
 - b. The amount;*
 - c. The location;*
 - d. The duration; and*
 - e. The service provider agency and provider;*
- (4) Be based on an individual service agreement written proposal that includes:*
 - a. A description of the services to be provided that also specifies the expenditures to be made;*
 - b. A line-item budget; and*
 - c. A process for measuring the individual's degree of satisfaction with the services provided;*
- (5) Not be provided by the spouse of an individual, except as provided in 517.10(g) below, or the parent of an individual where the individual is a minor child;*
- (6) Be provided by persons qualified pursuant to He-M 504 He-M 506.03 and He-M 525, as applicable in cases where services are provided by relatives other than parents or by friends; and*

(7) Be reimbursed in accordance with the process for each monthly for services provided as outlined in 517.05.

(b) Participant directed and managed services documentation shall include:

(1) Individual records, including:

a. Information about the individual that would be essential in case of an emergency, including that information specified in 517.09 (b)(1);

b. The portion of the individual's service agreement pertaining to participant directed and managed services, with any revisions;

c. Monthly progress notes;

d. Monthly notes describing the family's satisfaction with the services; and

e. Monthly financial statements provided to the individual and family by the service coordinator; and

(2) Detailed description of all services provided, including:

a. The date;

b. The activity or type of service;

c. The location;

d. The duration;

e. The provider agency and provider; and

f. Documentation required for the services provided as outlined in 517.09.

The Council is concerned that PDMS services are subject to caps that are not included for traditional services. This seems unfair. The Bureau needs to make sure that families are fully informed about their legal obligations as employers if they utilize PDMS services. With the new process to request additional funding, PDMS should not need to be used as a means to pay staff more or for providers to pass off their responsibilities to recruit and hire staff. The Council supports the work of the PDMS committee in this area. The Council believes that the provision of PDMS services could be improved and suggests focus groups with PDMS families, providers, and service coordinators to identify issues.

He-M 517.08 Non-Covered Services.

The following services shall not be fundable under home and community-based care waivers:

(a) Educational services or education programs for individuals who are under 221 years of age that are the responsibility of the local education authority;

(b) Post-secondary education, regardless of whether it leads to a degree;

(c) Sheltered workshop services; and

(d) Custodial care programs provided only to maintain an individual's basic welfare.

The Council recommends deleting "provided only to maintain an individual's basic welfare" and defining custodial care. This is confusing.

(e) Services that are recreational or diversional in nature; and

As noted above, the Council is considering a letter with concerns about this restriction at its meeting on September 20, 2023.

(f) Services which are available under the medicaid state plan; and

(g) Experimental or prohibited treatments.

He-M 517.097 Documentation.

The Council encourages the Bureau to talk to providers and service coordinators about documentation requirements. We recognize that some documentation is necessary but it also takes away from time to actually support the person with developmental disabilities.

(8) Copies of correspondence within the past year with the individual or guardian, service providers, physicians, attorneys, state and federal agencies, family members and others in the individual's life with whom the service coordinator has corresponded; and

The Council is particularly concerned about this provision as it seems very broad. In addition, the Council is concerned about the overuse of encrypted emails that are automatically deleted after a short period of time. The extra clicks and lack of ability to look back are difficult for families. Encrypted emails should be used when protected information is being shared, but not for basic emails like emails about scheduling appointments.

He-M 517.09 Appeals.

The right of a participant to appeal decisions to reduce, deny or terminate services is critical. The language here, referencing He-M 517.03 and He-M 517.08 (h), allows for appeals only related to eligibility decisions and prior authorizations. This is too narrow.

When appeals are allowed, it is important that participants are notified of their right to appeal, the notice is in plain language and includes all the reasons for the decision, and services are continued during the appeals process.

He-M 517.11 Waivers.

The Council believes that people with disabilities and families could benefit from additional information regarding waivers, including what is and is not in statute and therefore eligible for a waiver. The Council suggests a one-page document with this information.

As noted in previous rules comments, the Council recommends that information about any current waivers be available on the provider's website. This could include all waivers received, trended data on specific rules waivers and information about efforts to come into compliance with the waived rule. The rules should also set specific timelines for the Bureau to respond to waiver requests, ideally within 72 hours.

Additional General Comments

The Council recommends more detailed descriptions of services and provider qualifications in the waiver or somewhere in rule.

The service definitions included here can be confusing and it seems like some overlap. When the new waiver is written, the Council recommends clarifying the purpose and functions of each service. However, we want to make sure that no one loses services in this clarification.

The Council believes that maintaining and sustaining goals is important, and this should be allowed in all services possible. In practice, the Council believes that some individuals are required to create new goals each year to gain skills and the value of maintaining skills is not recognized. This is frustrating and discouraging. Additionally, the development of goals should start with the development of a true person-centered plan that is used to inform the service agreement.

In addition, the Council wants to encourage the Bureau to assess individual's goals each year. It is not okay to copy and paste the same service agreement without a discussion of current hopes, dreams and needs.

The Council believes that it is important to educate people with disabilities and family members about the new waiver services and is willing to help to do so.

Thank you for the opportunity to provide these comments.

Sincerely,

Stephanie Patrick, Council Chair

Isadora Rodriguez-Legendre, Council Vice-Chair