Title of Rule: Revision to the Medical Assistance Rule concerning Adding Community or Facility Based care to CLLI Respite Services, Section 8.504
Rule Number: MSB 18-08-08-A
Division / Contact / Phone: Office of Community Living / Kathleen Homan / 303-866-5749

## STATEMENT OF BASIS AND PURPOSE

1. Summary of the basis and purpose for the rule or rule change. (State what the rule says or does and explain why the rule or rule change is necessary).

   The Community Options Benefits Section would like to amend the current Children with Life Limiting Illness (CLLI) Waiver rule to add community and facility-based options as a billable location for Respite benefits. Current rule only allows respite in the family's home or in the home of an approved care provider. Community and Facility based respite was previously in the CLLI waiver but had been removed due to zero utilization. The Department recently received stakeholder feedback from family members, providers and agency advocates that this service is needed. A rule change is necessary in order to increase access to care and support families. The Department intends for this service to be effective on January 1, 2019.

2. An emergency rule-making is imperatively necessary

   ☐ to comply with state or federal law or federal regulation and/or
   ☐ for the preservation of public health, safety and welfare.

   Explain:

3. Federal authority for the Rule, if any:

   The Home and Community Based Services for Children with Life Limiting Illness program (HCBS-CLLI) in Colorado is authorized by a waiver of the amount, duration and scope of services requirements contained in Section 1902(a)(10)(B) of the Social Security Act. The waiver was granted by the United States Department of Health and Human Services, under Section 1915(c) of the Social Security Act.

4. State Authority for the Rule:

   25.5-1-301 through 25.5-1-303, C.R.S. (2017);
   25.5-5-305 and 10 CCR 2505 - 10.8.504.1.N and 10.8.504.2.F

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## REGULATORY ANALYSIS

1. Describe the classes of persons who will be affected by the proposed rule, including classes that will bear the costs of the proposed rule and classes that will benefit from the proposed rule.

   Only eligible and enrolled Members of the CLLI waiver and their families will be affected by this change. Only eligible and enrolled Members of the CLLI waiver and their families will benefit from this proposed rule. The proposed rule does not increase costs.

2. To the extent practicable, describe the probable quantitative and qualitative impact of the proposed rule, economic or otherwise, upon affected classes of persons.

   Current rule only allows for this service to be offered in the home. The qualitative impact of the rule change would be increased access to the community and increased socialization for the Member. This may be positive or negative depending on the individual. Respite is intended to provide short-term relief for the caregiver. Respite, outside of the home, may improve the caregiver's feelings of relief and comfort from the service. They may derive additional comfort having a community location for respite instead of having a caregiver welcomed into the family home. Facility based care may increase the caregiver's sense that an agency can adequately care for their family member instead of just one person in the family home. This service was previously in the waiver but eliminated due to low utilization and zero providers. The Department received assurances from the provider community that this service would be offered if approved.

3. Discuss the probable costs to the Department and to any other agency of the implementation and enforcement of the proposed rule and any anticipated effect on state revenues.

   There are no further costs to the Department from this proposed rule. The potential increase of service utilization is unknown at this time. Agencies must follow appropriate licensing, credentialing and enrollment procedures through CDPHE and the Department. This may increase an agency's administrative costs if they are not currently a provider.

4. Compare the probable costs and benefits of the proposed rule to the probable costs and benefits of inaction.

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The benefits of this rule include: increased community inclusion to Waiver Members, increased service providers in the community, increased access to services and increased choices of providers for Members and their families. There are no benefits for inaction but the probable costs of inaction include: ongoing service limitations for families, ongoing lack of choice in services for families and less community inclusion for Waiver Members. There are zero to minimal additional costs from this proposed rule. All potential benefits outweigh inaction as increasing access to care and access to services is invaluable.

5. Determine whether there are less costly methods or less intrusive methods for achieving the purpose of the proposed rule.

   None.

6. Describe any alternative methods for achieving the purpose for the proposed rule that were seriously considered by the Department and the reasons why they were rejected in favor of the proposed rule.

   None were proposed or rejected.

## 8.504 HOME AND COMMUNITY BASED SERVICES for CHILDREN WITH LIFE LIMITING ILLNESS WAIVER

### 8.504.05 Legal Basis

The Home and Community Based Services for Children with Life Limiting Illness program (HCBS-CLLI) in Colorado is authorized by a waiver of the amount, duration and scope of services requirements contained in Section 1902(a)(10)(B) of the Social Security Act. The waiver was granted by the United States Department of Health and Human Services, under Section 1915(c) of the Social Security Act. The HCBS-CLLI program is also authorized under state law at C.R.S. § 25.5-5-305 et seq. – as amended.

### 8.504.1 DEFINITIONS

A. Assessment means a comprehensive evaluation with the individual seeking services and appropriate collaterals (such as family members, advocates, friends and/or caregivers) conducted by the case manager, with supporting diagnostic information from the individual's medical provider to determine the individual's level of functioning, service needs, available resources, and potential funding resources. Case managers shall use the Department approved assessment tool to complete assessments.

B. Bereavement Counseling means counseling provided to the client and/or family members in order to guide and help them cope with the client's illness and the related stress that accompanies the continuous, daily care required by a child with a life-threatening condition. Enabling the client and family members to manage this stress improves the likelihood that the child with a life-threatening condition will continue to be cared for at home, thereby preventing premature and otherwise unnecessary institutionalization. Bereavement activities offer the family a mechanism for expressing emotion and asking questions about death and grieving in a safe environment thereby potentially decreasing complications for the family after the child dies.

C. Case Management means the assessment of an individual receiving long-term services and supports' needs, the development and implementation of a support plan for such individual, referral and related activities, the coordination and monitoring of long-term service delivery, the evaluation of service effectiveness and the periodic reassessment of such individual's needs.

D. Continued Stay Review (CSR) means a reassessment by the Single Entry Point case manager to determine the client's continued eligibility and functional level of care.

E. Cost Containment means the determination that, on an average aggregate basis, the cost of providing care in the community is less than or the same as the cost of providing care in a hospital.

F. Curative Treatment means medical care or active treatment of a medical condition seeking to affect a cure.

G. Expressive Therapy means creative art, music or play therapy which provides children the ability to creatively and kinesthetically express their medical situation for the purpose of allowing the client to express feelings of isolation, to improve communication skills, to decrease emotional suffering due to health status, and to develop coping skills.

H. Intake/Screening/Referral means the initial contact with individuals by the Single Entry Point agency and shall include, but not be limited to, a preliminary screening in the following areas: an individual's need for long term services and supports; an individual's need for referral to other

programs or services; an individual's eligibility for financial and program assistance; and the need for a comprehensive functional assessment of the individual seeking services.

I. Life Limiting Illness means a medical condition that, in the opinion of the medical specialist involved, has a prognosis of death that is highly probable before the child reaches adulthood at age 19.

J. Massage Therapy means the physical manipulation of muscles to ease muscle contractures, spasms, extension, muscle relaxation and muscle tension.

K. Palliative/Supportive Care is a specific program offered by a licensed health care facility or provider that is specifically focused on the provision of organized palliative care services. Palliative care is specialized medical care for people with life limiting illnesses. This type of care is focused on providing clients with relief from the symptoms, pain, and stress of serious illness, whatever the diagnosis. The goal is to improve the quality of life for both the client and the family. Palliative care is appropriate at any age (18 and under for this waiver) and at any stage in a life limiting illness and can be provided together with curative treatment. The services are provided by a Hospice or Home Care Agency who have received additional training in palliative care concepts such as adjustment to illness, advance care planning, symptom management, and grief/loss. For the purpose of this waiver, Palliative Care includes Care Coordination and Pain and Symptom Management.

1. Care Coordination includes development and implementation of a care plan, home visits for regular monitoring of the health and safety of the client and central coordination of medical and psychological services. The Care Coordinator will organize the multifaceted array of services. This approach will enable the client to receive all medically necessary care in the community with the goal of avoiding institutionalization in an acute care hospital. Additionally, a key function of the Care Coordinator will be to assume the majority of responsibility, otherwise placed on the parents, for condensing, organizing, and making accessible to providers, critical information that is related to care and necessary for effective medical management. The activities of the Care Coordinator will allow for a seamless system of care. Care Coordination does not include utilization management, that is review and authorization of service requests, level of care determinations, and waiver enrollment, provided by the case manager at the Single Entry Point.

2. Pain and Symptom Management means nursing care in the home by a registered nurse to manage the client's symptoms and pain. Management includes regular, ongoing pain and symptom assessments to determine efficacy of the current regimen and available options for optimal relief of symptoms. Management also includes as needed visits to provide relief of suffering, during which, nurses assess the efficacy of current pain management and modify the regimen if needed to alleviate distressing symptoms and side effects using pharmacological, non-pharmacological and complementary/supportive therapies.

L. Prior Authorization Request (PAR) means the Department's prescribed form to authorize services.

M. Professional Medical Information Page (PMIP) means the medical information signed by a licensed medical professional used as a component of the Assessment to determine the client's need for institutional care.

N. Respite Care means services provided to an eligible client who is unable to care for himself/herself on a short-term basis because of the absence or the need for relief of those persons normally providing care. Respite Care ~~is provided in the client's residence and~~ may be

provided through ~~by~~ different levels of care ~~providers~~ depending upon the needs of the client. Respite care may be provided in the client's residence, in the community, or in an approved respite center location.

O. Support Planning means the process of working with the individual receiving services and people chosen by the individual to identify goals, needed services, individual choices and preferences, and appropriate service providers based on the individual seeking or receiving services' assessment and knowledge of the individual and of community resources. Support planning informs the individual seeking or receiving services of his or her rights and responsibilities.

P. Therapeutic Life Limiting Illness Support means grief/loss or anticipatory grief counseling that assist the client and family to decrease emotional suffering due to the client's health status, to decrease feelings of isolation or to cope with the client's life limiting diagnosis. Support is intended to help the child and family in the disease process. Support is provided to the client to decrease emotional suffering due to health status and develop coping skills. Support is provided to the family to alleviate the feelings of devastation and loss related to a diagnosis and prognosis for limited lifespan, surrounding the failing health status of the client, and impending death of a child. Support is provided to the client and/or family members in order to guide and help them cope with the client's illness and the related stress that accompanies the continuous, daily care required by a terminally ill child. Support will include but is not limited to counseling, attending physician visits, providing emotional support to the family/caregiver if the child is admitted to the hospital or having stressful procedures, and connecting the family with community resources such as funding or transportation.

Q. Utilization Review means approving or denying admission or continued stay in the waiver based on level of care needs, clinical necessity, amount and scope, appropriateness, efficacy or efficiency of health care services, procedures or settings.

**8.504.2 BENEFITS**

8.504.2.A. Home and Community Based Services under the Children with Life Limiting Illness Waiver (HCBS-CLLI) benefits shall be provided within Cost Containment.

8.504.2.B. Therapeutic Life Limiting Illness Support may be provided in individual or group setting.

1. Therapeutic Life Limiting Illness Support shall only be a benefit if it is not available under Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) coverage, Medicaid State Plan benefits, third party liability coverage or by other means.

2. Therapeutic Life Limiting Illness Support is limited to the client's assessed need up to a maximum of 98 hours per annual certification period.

8.504.2.C. Bereavement Counseling shall only be a benefit if it is not available under Medicaid EPSDT coverage, Medicaid State Plan benefits, third party liability coverage or by other means.

1. Bereavement Counseling is limited to the client's assessed need and is only billable one time.

2. Bereavement Counseling is initiated and billed while the child is on the waiver but may continue after the death of the child for a period of up to one year.

8.504.2.D. Expressive Therapy may be provided in an individual or group setting.

1. Expressive Therapy is limited to the client's assessed need up to a maximum of 39 hours per annual certification period.

8.504.2.E. Massage Therapy shall be provided in an individual setting.

1. Massage Therapy shall only be used for the treatment of conditions or symptoms related to the client's illness.

2. Massage Therapy shall be limited to the client's assessed need up to a maximum of 24 hours per annual certification period.

8.504.2.F. Respite Care shall be provided in the home, in the community, or in an approved respite center location of an eligible client on a short term basis, not to exceed 30 days per annual certification as determined by the Department approved Assessment. Respite Care shall not be provided at the same time as state plan Home Health or Palliative/Supportive Care services.

1. Respite Care services include any of the following in any combination necessary according to the Support Planning services:

a. Skilled nursing services;

b. Home health aide services; or

c. Personal care services

8.504.2.G. Palliative/Supportive Care shall not require a nine month terminal prognosis for the client and includes:

1. Pain and Symptom Management; and

2. Care Coordination

8.504.2.H. HCBS-CLLI clients are eligible for all other Medicaid state plan benefits, including Hospice and Home Health.

**8.504.3 NON-BENEFIT**

8.504.3.A. Case Management is not a benefit of the HCBS-CLLI waiver. The Single Entry Point (SEP) provides case management services as an administrative activity.

**8.504.4 CLIENT ELIGIBILITY**

8.504.4.A. An eligible client shall:

1. Be financially eligible.

2. Be at risk of institutionalization into a hospital as determined by the SEP case manager using the Department approved assessment tool.

3. Meet the target population criteria as follows:

a. Have a life-limiting diagnosis, as certified by a physician on the Department prescribed form, and

b. Have not yet reached 19 years of age.

8.504.4.B A client shall receive at least one HCBS-CLLI waiver benefit per month to maintain enrollment in the waiver.

1. A client who has not received at least one HCBS-CLLI waiver benefit during a month shall be discontinued from the waiver.

2. Case Management does not satisfy the requirement to receive at least one benefit per month on the HCBS-CLLI waiver.

## 8.504.5 WAIT LIST

8.504.5.A. The number of clients who may be served through the waiver at any one time during a year shall be limited by the federally approved HCBS-CLLI waiver document.

8.504.5.B. Applicants who are determined eligible for benefits under the HCBS-CLLI waiver, who cannot be served within the capacity limits of the federally approved waiver, shall be eligible for placement on a wait list maintained by the Department.

8.504.5.C. The SEP case manager shall ensure the applicant meets all criteria as set forth in Section 8.504.4.A prior to notifying the Department to place the applicant on the wait list.

8.504.5.D. The SEP case manager shall enter the client's Assessment and Professional Medical Information Page data in the Benefits Utilization System (BUS) and notify the Department by sending the client's enrollment information, utilizing the Department's approved form, to the program administrator.

8.504.5.E. The date and time of notification from the SEP case manager shall be used to establish the order of an applicant's place on the wait list.

8.504.5.F. Within five working days of notification from the Department that an opening for the HCBS-CLLI waiver is available, the SEP case manager shall:

1. Reassess the applicant for functional level of care using the Department approved assessment tool if the date of the last Assessment is more than six months old.

2. Update the existing Department approved assessment tool data if the date is less than six months old.

3. Reassess for the target population criteria.

4. Notify the Department of the applicant's eligibility status.

## 8.504.6 PROVIDER ELIGIBILITY

8.504.6.A. Providers shall conform to all federal and state established standards for the specific service they provide under the HCBS-CLLI waiver, enter into an agreement with the Department. Providers must comply with the requirements of 10 CCR 2505-10, Section 8.130.

8.504.6.B. Licensure and required certification for providers shall be in good standing with their specific specialty practice act and with current state licensure regulations.

8.504.6.C. Individuals providing Therapeutic Life Limiting Illness Support and Bereavement Counseling shall enroll with the fiscal agent or be employed by a qualified Medicaid home health or hospice agency.

8.504.6.D. Individuals providing Therapeutic Life Limiting Illness Support and Bereavement Counseling shall be one of the following:

1. Licensed Clinical Social Worker (LCSW)

2. Licensed Professional Counselor (LPC)

3. Licensed Social Worker (LSW)

4. Licensed Independent Social Worker (LISW)

5. Licensed Psychologist; or

6. Non-denominational spiritual counselor, if employed by a qualified Medicaid home health or hospice agency.

8.504.6.E. Individuals providing Expressive Therapy shall enroll with the fiscal agent or be employed by a qualified Medicaid home health or hospice agency.

1. Individuals providing Expressive Therapy delivering art or play therapy services shall meet the requirements for individuals providing Therapeutic Life Limiting Illness Support services and shall have at least one year of experience in the provision of art or play therapy to pediatric/adolescent clients.

2. Individuals providing Expressive Therapy delivering music therapy services shall hold a Bachelor's, Master's or Doctorate in Music Therapy, maintain certification from the Certification Board for Music Therapists, and have at least one year of experience in the provision of music therapy to pediatric/adolescent clients.

8.504.6.F. Massage Therapy providers shall have an approved registration and be in good standing with the Colorado Office of Massage Therapy Registration.

8.504.6.G. Individuals providing Palliative/Supportive Care services shall be employed by or working under a formal contract with a qualified Medicaid hospice or home health agency.

8.504.6.H. Individuals providing Respite services shall be employed by a qualified Medicaid home health, hospice or personal care agency.

## 8.504.7 PROVIDER RESPONSIBILITIES

8.504.7.A. HCBS-CLLI providers shall have written policies and procedures regarding:

1. Recruiting, selecting, retaining and terminating employees.

2. Responding to critical incidents, including accidents, suspicion of abuse, neglect or exploitation and criminal activity appropriately, including reporting such incidents pursuant to section 19-3-307 C.R.S. (2016).

8.504.7.B. HCBS-CLLI providers shall:

1. Ensure a client is not discontinued or refused services unless documented efforts have been made to resolve the situation that triggers such discontinuation or refusal to provide services.

2. Ensure client records and documentation of services are made available at the request of the case manager.

3. Ensure that adequate records are maintained.

   a. Client records shall contain:

      i. Name, address, phone number and other identifying information for the client and the client's parent(s) and/or legal guardian(s).

      ii. Name, address and phone number of the SEP and the Case Manager.

      iii. Name, address and phone number of the client's primary physician.

      iv. Special health needs or conditions of the client.

      v. Documentation of the specific services provided which includes:

         1. Name of individual provider.

         2. The location for the delivery of services.

         3. Units of service.

         4. The date, month and year of services and, if applicable, the beginning and ending time of day.

         5. Documentation of any changes in the client's condition or needs, as well as documentation of action taken as a result of the changes.

         6. Financial records for all claims, including documentation of services as set forth at 10 C.C.R. 2505-10, Section 8.040.02.

         7. Documentation of communication with the client's SEP case manager.

         8. Documentation of communication/coordination with other providers.

   b. Personnel records for each employee shall contain:

      i. Documentation of qualifications to provide rendered service including screening of employees in accordance with Section 8.130.35.

      ii. Documentation of training.

      iii. Documentation of supervision and performance evaluation.

iv. Documentation that an employee was informed of all policies and procedures as set forth in Section 8.504.7.A.

v. A copy of the employee's job description.

4. Ensure all care provided is coordinated with any other services the client is receiving.

a.

## 8.504.8 PRIOR AUTHORIZATION REQUESTS

8.504.8.A. The SEP case manager shall complete and submit a PAR form within one calendar month of determination of eligibility for the HCBS-CLLI waiver.

8.504.8.B. All units of service requested shall be listed on the Support Planning form.

8.504.8.C. The first date for which services may be authorized is the latest date of the following:

1. The financial eligibility start date, as determined by the financial eligibility site.

2. The assigned start date on the certification page of the Department approved assessment tool.

3. The date, on which the client's parent(s) and/or legal guardian signs the Support Planning form or Intake form, as prescribed by the Department, agreeing to receive services.

8.504.8.D. The PAR shall not cover a period of time longer than the certification period assigned on the certification page of the Department approved assessment tool.

8.504.8.E. The SEP case manager shall submit a revised PAR if a change in the Support Planning results in a change in services.

8.504.8.F. The revised Support Planning document shall list the service being changed and state the reason for the change. Services on the revised Support Planning document, plus all services on the original document, shall be entered on the revised PAR.

8.504.8.G. Revisions to the Support Planning document requested by providers after the end date on a PAR shall be disapproved.

8.504.8.H. A revised PAR shall not be submitted if services on the Support Planning document are decreased, unless the services are being eliminated or reduced in order to add other services while maintaining cost-effectiveness.

8.504.8.I. If services are decreased without the client's parent(s) and/or legal guardian agreement, the SEP case manager shall notify the client's parent(s) and/or legal guardian of the adverse action and appeal rights using the LTC 803 form in accordance with the 10 day advance notice period.

## 8.504.9 REIMBURSEMENT

8.504.9.A. Providers shall be reimbursed at the lower of:

1. Submitted charges; or
2. A fee schedule as determined by the Department.