Adirondack Health Institute

Lead Empower Innovate

POLICY AND PROCEDURE

Title: Palliative Care – Counseling and Support Services and Health Home Care Management

Department: Health Home

Intended Population: Health Home Serving Children

Effective Date: 6/1/2022

Date Revised: 1/1/2023, 6/1/2024

DOH Policy: CW0015

Purpose of Policy

This policy provides guidance to Children's Waiver Health Home Care Managers (HHCMs) regarding the requirements for delivering and documenting Palliative Care - Counseling and Support Services for families of children and youth with a terminal or life-threatening illness who is enrolled in the Children's Waiver.

This policy is applicable to youth and children enrolled in the Children's Waiver Home and Community Based Services and Health Home Care Managers (HHCMs) serving Children's Waiver enrolled and eligible participants that have a terminal illness or a life-threatening illness and meet the requirements below.

Scope

1. This policy must be distributed to all AHI Health Home Program staff and all subcontracting Health Home Service Providers.
2. All recipients of this policy must acknowledge their receipt and understanding of the policy by referring any questions, problems, or compliance issues with the policy within ten days of the issue date to the AHI's Health Home Assistant Director.
3. All questions regarding this policy or its implementation may be directed to the AHI Health Home Assistant Director

Statement of Policy

AHI shall develop, disseminate, and review at least annually a Palliative Care Policy that addresses purpose, scope, roles and responsibilities, management commitment, coordination among organization entities, and compliance. AHI shall formalize documented procedures to facilitate the implementation of the Palliative Care Policy.

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Definitions

Counseling and Support Services: provide help for participants and their families to manage and cope with the diagnosis and grief related to the participant's end-of-life experience. Children/youth with a terminal or life-threatening illness, and their families, cope with grief and loss in a variety of ways and may need various kinds of support over time, including counseling, support groups, and other services.

AHI HH: AHI Health Home, a designated lead Health Home by the New York State Department of Health

Child: A person age 21 or younger who is not on AOT (Assisted Outpatient Treatment).

Health Home Network Partners: The group of medical, behavioral, social services, and other community-based organizations by which a Health Home Participant receives services to address needs identified in the comprehensive care management plan developed by the Health Home Participant's AHI Health Home Services Provider.

Health Home Participant: A Health Home Candidate who is participating in the AHI Health Home and is assigned to an AHI Health Home Services Provider for care management.

Health Home Service Provider: An organization that has a fully executed contract (the "Health Home Services Provider Agreement") with the Adirondack Health Institute to provide health home outreach and/or care management services.

Care Management Record System: A structured information system, maintained by the Adirondack Health Institute Health Home (AHIHH), and made available for Health Home Service Providers and Health Home Network Partners to utilize, as applicable and appropriate to their role in the Health Home.

Children and Youth Evaluation Service (C-YES): C-YES is the State-designated Independent Entity which conducts HCBS/Level of Care (LOC) eligibility determinations and provides Medicaid application assistance for children who are eligible for HCBS not yet enrolled in Medicaid. C-YES also develops an HCBS POC, refers eligible children for HCBS, and monitors access to care for children who opt out of Health Home care management.

Care Team or Multi-disciplinary Team: The providers, identified family supports, family members, managed care plan, and other individuals or entities that the child/youth or family identified to be involved in the care coordination and service provision development.

Duration: Describes how long the service will be delivered to the child and/or family. The duration of the service should correspond to the abilities of the child/family and be reflective of the billing unit identified by service.

Family: Within this document the term "family" is used and defined as the primary caregiving unit inclusive of the wide diversity of primary caregiving units in our society. Family is a birth, foster, adoptive or self-created unit of people residing together, with significant attachment to the individual, consisting

of adult(s) and/or child(ren), with adult(s) performing duties of parenthood/caregiving for the child(ren) even if the individual is living outside of the home.

Frequency: Outlines how often the service will be offered to the child and/or family.
Services may be delivered on a weekly, biweekly or monthly basis, according to the needs of the child and family.

Home and Community Based Services (HCBS)/Level of Care (LOC) Eligibility Determination: A tiered assessment where multiple factors must be met for child's HCBS/LOC eligibility to be determined. To access Children's HCBS, a child must meet target population, risk factors, and functional criteria as described in the Children's Waiver. The HCBS/LOC Eligibility Determination is housed within the Uniform Assessment System (UAS).

Scope: The service components and interventions being provided and utilized to address the identified needs of the child.

Workforce member: means Employees, board members, volunteers, interns, independent contractors, vendors, and other persons whose conduct, in the performance of work for a covered entity, is under the direct control of such entity, whether or not they are paid by the covered entity. This includes full and part time employees, affiliates, associates, volunteers, and staff from third party entities who provide service to the covered entity.

Background

The Palliative Care Program Policy at AHI is intended to facilitate the effective implementation of the processes necessary to meet the Health Home Program standards and requirements as stipulated by the NYS DOH, federal regulations, and best practices. This policy directs that AHI meet these requirements.

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Palliative Care Counseling and Support Services has historically supported family members facing the terminal diagnosis of their child/youth who was enrolled in the Children's Waiver. As of December 1, 2021, families may receive Palliative Care Bereavement Counseling up to six (6) months after the passing of the enrolled participant and/or Palliative Care Health Home Care Management services for one (1) additional month following the passing of a participant enrolled in the Children's Waiver.

This policy provides guidance to HHCMs regarding the Children's Waiver Counseling and Support Services ***and*** Palliative Care Health Home Care Management are intended to support the caregivers, siblings, and other family members after the passing of an eligible and enrolled Children's Waiver participant that was diagnosed with a terminal illness or a life-threatening illness.

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Note: These services can be offered at any point after a Children's Waiver participant is diagnosed with a terminal or life-threatening illness.

When an enrolled participant is disenrolled from Medicaid services or is deceased, Medicaid services typically end because payment of the service is predicated upon the Medicaid enrollment. However, Counseling and Support Services may continue after the participant's passing.

- Families may receive Palliative Care Counseling and Support Services under either the Medicaid State Plan Hospice authority or Palliative Care Bereavement Services under the Children's Waiver, so long as the services are not duplicative.

    - Counseling and support services are available for those participants in receipt of hospice care through a hospice provider under the State Plan. counseling support services are included as a component of the hospice service for those participants who are receiving services with a hospice care provider.

    - This policy outlines the Counseling and Support Services under the Children's Waiver. Palliative Care Counseling and Support Services are intended to provide continued support after the passing of the participant. ***The service must be added to the Plan of Care and the begin date of service must occur prior to the participant's passing. The claim must be submitted within 30 days of the participant's death.***

Counseling and Support Services Component:

Palliative Care Counseling and Support Services are delivered to a participant and their family to cope with and prepare for the end-of-life experience. To address the need for families to receive continued support after the passing of their child, Bereavement Counseling is now available for up to six (6) months after the passing of the enrolled participant.

Palliative Care Counseling and Support Services can be delivered:

To the participant with a terminal or life-threatening illness **and** the participant's identified family members *prior* to the passing of the participant,

AND/OR

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To the participant's identified family *after* the passing of participant, if the HCBS providers service plan and the care managers plan of care (POC) denotes the service as outlined below.

To receive Palliative Care Counseling and support services after the passing of the eligible and enrolled participant, the family must initiate the service **prior to** the participant's passing. A determination of the needed services and request by the family must be made as part of the HCBS service plan for the provider to bill the service, which includes counseling for up to six (6) months after the passing of the participant. Additionally, the six (6) months of counseling must be documented in the participant's Health Home POC.

Determination of Counseling and Support Services Needs

The Palliative Care Counseling and Support Services provider must conduct an **initial need assessment** to determine the needs of the participant and their family while considering the social, spiritual, and cultural factors that may impact their ability to cope with the participant's terminal or life-threatening illness and death. This review should be incorporated into the provider's service plan that outlines the frequency, scope, and duration of counseling to be provided *and* that service plan should be incorporated into the HCBS care management POC. For families to receive Counseling Support Services after the passing of their child/youth, the service must be included in the POC ***prior*** to the participant's passing.

To enhance engagement with, and support for, the family, care managers should have 1-2 documented discussions to identify the needs of the family, even if they ultimately choose not to use the Counseling Support Services after the child passes away. The conversations should include care management roles as well as incorporating the needs assessment for Counseling and Support Services by a licensed mental health practitioner. These needs may not be apparent prior to experiencing a loss, but they should be incorporated into the POC. Counseling and Support Services and post-mortem service plans should be updated regularly and be incorporated into the final POC. The Care Manager should ensure that the provider implements the service plan.

Example – Plan of Care:

1) Palliative Care Counseling and Support Services will be provided bi-weekly for the participant for 3 months with family involvement to address coping strategies regarding the terminal diagnosis.

2) Palliative Care Counseling and Support Services will be provided bi-weekly for up to six months to the participant's family due to the passing of the participant.

The **Palliative Care HCBS Provider** will utilize the following to assist with the Counseling and Support Services review and development of the service plan:

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Determination of Counseling and Support Services Needs

The participant is determined to have a terminal illness or a life-threatening illness and the participant and/or family members have at least one of the following:

1) a degree of anxiety and depressive responses and triggers of such responses
2) other affective responses such as guilt and helplessness
3) somatic concerns and dysregulation
4) psychiatric symptoms including orientation and mental status, PTSD (post-traumatic stress disorder) in both full-blown and partial forms, and suicidal ideation
5) self-esteem issues
6) effects on the individual's ability to work or perform major life tasks
7) effects on the management of family relationships, including the relationship to spouse or partner, to other children, and/or to the extended family

Counseling and Support Services should incorporate guidance that accounts for:

> The nature and degree of involvement in interpersonal relationships outside the family the meaning framework or structure in which the bereaved is embedded and its current power the degree to which the bereaved can invest emotional energy in life tasks and the type of life tasks that are engaged.

For family members, the relationship to the terminally ill participant and the Counseling and Support Services needs are reviewed in relation to:

1) the ability to cope with the terminal diagnosis and management of treatment
2) the degree of preoccupation with the diagnosis and the illness
3) the degree of guilt, helplessness, or ability to manage the illness
4) the extent in which the illness is impacting the functioning, activities, and daily life needs for the siblings, caregivers, and other family members

For family members, the relationship to the deceased participant and the Counseling and Support Services needs are reviewed in relation to:

1) the degree of preoccupation with memories and thoughts of the deceased
2) the extent to which the description of the deceased is characterized by an inability or unwillingness to express the personal feelings brought about by the death
3) the degree of idealization of the deceased
4) the report of psychological conflict or contradictions in the relationship
5) the degree and type of positive affect and emotion
6) the degree and type of negative emotion toward the deceased
7) the degree of closeness or distance from the relationship and experience of the deceased
8) the affective experience when discussing the deceased (e.g., a parent who might say, “I always feel guilty thinking about how my son died”)

9) the presence of previously described grief phases of shock, seeking reminders of the deceased, disorganization, and restoration of a coherent life flow the manner in which the deceased is memorialized both publicly and within the family Social, spiritual, and cultural factors that may impact a family member or other individual's ability to cope with the participant's death may include, but are not limited to:

- History of previous losses
- Religion
- Family problems
- Community
- Financial and/or legal concerns
- Communication issues
- Drug and alcohol abuse
- Health concerns
- Mental health issues
- Presence or absence of a support system
- Feelings of despair, anger, guilt, or abandonment

These issues may not be readily apparent during the initial Counseling Support and Services review but must be considered and should be incorporated into the provider's service plan.

<u>The broad elements of comprehensive psychological and emotional care include the following:</u>

- Evaluation of the child's psychological status and identification of psychological symptoms or disorders
- Provision of appropriate psychotherapy, psychotropic medications, or behavioral interventions as an integral part of the participant's overall care
- Advice for the participant's physician, parents, and others on additional strategies or steps that they can take to manage or minimize emotional distress
- Evaluation of the participant's parents and siblings (and sometimes other family members) for psychological symptoms
- Referral as appropriate to support groups for ill children/youth, healthy siblings and parents that allow them to share experiences in living with serious illness
- Bereavement support for the family after the participant's death

<u>Care Coordination Component: Medical Notifications and Related Tasks</u>

In addition to (but not contingent upon) Children's Waiver Counseling and Support Services, the family may receive Health Home care management services for an additional one (1) month after a participant in the Children's Waiver passes away, in accordance with this policy. Palliative Care Management is intended to assist with provider notifications and managing discontinuation of services after a child's passing.

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When a participant dies, particularly a participant who was terminally ill or had a life-threatening illness, families are often too emotionally stressed and overwhelmed to perform the multiple notifications and service discontinuations needed. Medically complex children/youth often have 10 to 15 medical specialists, 2 to 3 Durable Medical Equipment (DME) and supply vendors, 1 or 2 different pharmacies or specialty pharmacies, private duty nurses and/or multiple agencies, and various school contacts. In addition, the family needs to notify the Local Department of Social Services (LDSS), the insurance carrier, and/or Medicaid Managed Care Plan (MMCP). The Health Home care manager (HHCM) can assist with these tasks to support the family.

The POC, developed by the HHCM, should include the medical notifications and other related tasks that need to occur in the 30 days after the participant passes.

Care Management activities may include but are not limited to:

- Contacting all DME2 providers to determine whether the equipment is owned or rented
  - If owned, (if parent chooses) arrange removal from home
  - If rented, arrange for pick-up by vendors
  - If borrowed, arrange for item[s] to be returned to owner

- Arranging for all disposable supplies to be donated and transported (since vendors are prohibited from taking back supplies).
- Notifying all nursing / home care providers, including Fiscal Intermediary agencies
- Notifying all physicians and pharmacies
- Contacting school district / Committee on Special Education (CSE) team, Early Intervention Program (EIP) and/or therapy providers
- Notifying LDSS, MMCP, and insurance carrier [if applicable]
- Notifying Office for People with Developmental Disabilities (OPWDD) [if applicable]
- Removing Environmental Modifications – there are often items such as chair lifts or wheelchair ramps that families want removed from their homes, and they may want to know how / where to sell their modified vehicle.
- Assisting with locating funding for final expenses
- Providing linkage to bereavement groups and/or sibling support groups as well as ensuring that Counseling co and Support Services continues under the waiver/hospice benefit
- Notifying personal contacts as requested

These needs may not be readily apparent during the initial needs but should be incorporated into the Health Home POC.

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Plan of Care

The care management POC must indicate the specific services that will be provided (including post-mortem counseling and Support Services and assistance with medical notifications), individuals who would receive the services, and the frequency, scope, and duration of the services. The POC should be reviewed and updated up until the participant's death to support any changes in the family's needs. The Care Manager should ensure that any Counseling and Support Services is delivered in a manner consistent with the POC in effect at the time of the participant's death.
The POC must reflect the needs of the family and services that the provider will deliver to the family within the scope of the HCBS definition as outlined in this policy and HCBS Manual.

Example for Plan of Care:
1) Palliative Care Counseling and Support Services will be provided by the Health Home care manager for one month after the passing of the participant to assist with medical notification and other related tasks for the family.
2) Palliative Care Counseling and Support Services will be provided bi-weekly by the HCBS provider for up to six months to the participant's family due to the passing of the participant

Palliative Care Counseling and Support Services must be provided by a professional with experience or education in grief and loss counseling, per the Children's HCBS Manual. Assistance with medical notifications and other related tasks must be provided by a Health Home Care Manager. Billable services must be documented in the Service Plan, including the needs assessment, and in the Plan of Care.

Billing Component

1. Claims for payment for Health Home care coordination provided during the month of the participant's death must be dated prior to and submitted within 30 days of the participant's passing. Please note a claim with a date after the participant's death cannot be submitted.
2. Add the member's monthly billing instance to the Medicaid Analysists Performance Portal Health Home Tracking System (MAPP HHTS) to indicate that a billable Health Home service was provided during that member month.
3. The separate Health Home upstate/downstate rate code based upon acuity (below) is allowed for an additional unit to be billed along with the regular Health Home PMPM within 30 days of the participant's passing. This claim will not be reflected within the MAPP HHTS.
4. This additional rate code will allow for the additional month of care coordination for the month after the child/youth's passing to assist the family as outlined above.
5. The member's segment within the MAPP HHTS must be ended with the last day of the month in which the member passed.

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Service	Rate Code	Procedure Code	Unit Measure	Unit Limit
Palliative Care Counseling and Support Services	8017 – Counseling	90832	30 minutes	Limited to the lesser of 10 units per month or 120 units per calendar year
Bereavement Assessment and Counseling	7952 – Assess/Counseling	96156	Needs assessment and up to six (6) months of Counseling and Support Services	1 unit/calendar year Per member
Health Home Care Management Based Upon Acuity	7946 – HH Upstate[3] Low 7947 – HH Upstate Med 7948 – HH Upstate High 7949 – HH Downstate[4] Low 7950 – HH Downstate Med 7951 – HH Downstate High	96156	Care Coordination for one (1) month	

Contact Person: Assistant Director, Health Home

Responsible Person: Health Home Service Provider

Reviewed By: Director, Care Management and Health Home

Approved By: Chief Compliance Officer