



Department
of Health

Palliative Care Services: Addressing Provider Capacity

For HCBS Providers

July 2022

Purpose

- Children's Waiver Development of Palliative Care Services
- Defining the Array of Services
- Building Provider capacity statewide
- Response to feedback from HCBS providers
- How HCBS providers can expand service provision to include Palliative Care Services for children/youth

Children's Waiver Palliative Care Development

- When designing the Children's Waiver Palliative Care Services - NYS utilized feedback from stakeholders and previous waiver recipients
- Based upon that feedback:
 - Expanded the array of Palliative Care Services
 - Be able to serve any child in the Waiver that meets the criteria, not just medically fragile children/youth
 - Removed the end-of-life requirement
- NYS continues to receive feedback regarding these services and have been making additional adjustment as appropriate to serve children/youth within the Waiver, and to obtain the providers needed to build capacity.

Children's Waiver Palliative Care Services

- The set of services are specialized medical care focused on providing relief from the symptoms and stress of a chronic condition or life-threatening illness.
- The goal is to improve quality of life for both the child/youth and the family.
- The services are provided by a specially-trained team of doctors, nurses, social workers, and other specialists who work together with a child/youth's doctors to provide an extra layer of support.
- It is appropriate at any stage of a chronic condition or life-threatening illness and can be provided along with curative treatment.
- Children/youth must meet Level of Care (LOC) functional criteria and suffer from the symptoms and stress of chronic medical conditions or illnesses.

Four Components of Palliative Care

- Expressive Therapy
- Massage Therapy
- Pain and Symptom Management
- Counseling and Support Services

Expressive Therapy

- Expressive Therapy (art, music, and play) helps children/youth better understand and express their reactions through creative and kinesthetic treatment.
- The use of expressive therapy assists children/youth to feel empowered in their own creativity, control, and aid in their communication of their feelings while handling a chronic condition and/or life-threatening illness.
- Music, art, and/or play therapy can help the child/youth to find a positive means to express their feelings.

Massage Therapy

- Massage Therapy is used to improve muscle tone, circulation, range of motion, and address physical symptoms related to illness.
- It will provide physical and emotional comfort, pain management, and restore the idea of healthy touch for children/youth who are dealing with treatments that may cause pain from interventions, ongoing and/or past trauma.

Pain and Symptom Management

- Pain and Symptom Management consist of relief and/or control of the child/youth's suffering related to their illness or condition.
- It is important to aide in providing relief from pain and symptoms and/or controlling pain, symptoms, and side effects related to chronic conditions or life-threatening illness a child/youth is enduring.
- This management is also an important part of humanely caring for the child/youth's pain and suffering but helping the child/youth and family cope and preserve their quality of life at a difficult time.

Counseling and Support Services

- Formerly known as: Bereavement Service
- The Children's Waiver has enhanced Counseling and Support Services and Health Home care management to support the caregivers, siblings, and other family members, as follows:
 - *provide counseling and support to the child and family to deal with the symptoms and stress of a chronic condition or life-threatening illness,*
 - *provide continued counseling for up to six (6) months to the child's family after the child passes, and*
 - *continue to provide Health Home Care Management to support the family for a period of 30 days after the child passes*
- Counseling and Support Services are inclusive for those participants in receipt of hospice care through a hospice provider, if it is not duplicative.

Provider Interest of Services

- An HCBS provider interested in being designated to provider Palliative Care Services, has their own discretion in determining which component(s) they are interested in providing.
 - A provider can provide all four services, one service, or a combination of services.

Call to Action

- Currently in NYS there are only 4 designated providers of HCBS Palliative Care services, serving across 7 sites:
 - All 7 sites provide counseling and support services and expressive therapy;
 - Of those 7, only 3 sites provide message therapy and pain and symptom therapy; and,
 - 143 children are currently receiving at least one service.
- Current designated providers are located: NYC, Bronx, Nyack, New Hyde Park, and Buffalo

Children's Waiver Amendment

- Based upon continued dialogue with stakeholders and assessing the needs of Waiver recipients, NYS has made additional changes to the Waiver through Waiver Amendments:
 - Palliative Care Bereavement services title was changed to reflect the service and all that it encompassed – Counseling and Support Services
 - Comparison rates were evaluated and prior to any enhanced rates that are occurring in 2022, rates were increased
 - Qualifications and years of experiences has been adjusted for some of the services based on provider feedback
 - Future Amendment will remove specific years of experience language “working with the medically fragile population”

Provider Feedback

Please share your interest

What other adjustments would be needed to the service?

Other suggestions, comments, and feedback to develop provider capacity for these services?

Additional Stakeholder Engagement

- DOH will be forming a Palliative Care stakeholder workgroup to assist in improving and implementing this service.
 - HCBS Providers
 - Managed Care Plans
 - Family members
 - Other Providers and relevant stakeholders
- Information on these stakeholder workgroups will be forthcoming and announced through our HCBS distribution list.
- HCBS providers interested in joining this workgroup should contact DOH at: BH.transition@health.ny.gov

How to update your HCBS Designation

- For any questions and/or to request to update your HCBS Provider Designation Application to include Palliative Care: Counseling and Support Services, please submit to the OMH Designation mailbox: OMH-Childrens-Designation@omh.ny.gov
- DOH will be available to meet individually with any providers who are interested in further discussion. Please submit your request to the Behavioral Health BML at: BH.transition@health.ny.gov

For Information

- Find guidance, policies, forms, webinars, and more on the **NYS DOH 1915c Children's Waiver** webpage located at:

https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/children/1115_waiver_amend.htm

- **Children's Home and Community Based Services Manual**

https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/children/docs/hcbs_manual.pdf

- **Children's Consolidated Waiver Services (HCBS) - Rate Summary effective 4/1/2022**

[Children's Consolidated Waiver Services \(HCBS\) \(ny.gov\)](#)



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