



Department
of Health

Children's Waiver Palliative Care Follow-up Discussion

November 14, 2022

Agenda

- Purpose
- Children's HCBS Palliative Care Services
- Defining Provider Capacity Statewide
- Group Discussion
- Other Service Strategies
- Follow Up
- Appendix

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Purpose of Today's Discussion

NYS DOH has a Children's Waiver that was a consolidation of 6 Children's Waivers in NYS. The Palliative suite of services, were not in any of the previous waivers, but were built due to stakeholder feedback regarding the needs of children/youth.

The discussion today.....

To work collaboratively together
to determine strategies to **BUILD**
Service Capacity

Identify providers and
provider types for this
population of children
and youth

Children's HCBS Palliative Care Services

- Palliative Care Services are specialized medical care focused on providing relief from the symptoms and stress of a chronic condition or life-threatening illness.
 - The goal of Palliative Care Services is to improve quality of life for both the child/youth and the family.
 - Palliative Care 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.
- Providers of Palliative Care Services must be designated by NYS designation team.
- Palliative Care Services are paid through the member's Medicaid Managed Care Plan (MMCP) or Fee-for-Service (FFS), if the child/youth is not in Plan.

HCBS Palliative Care Services

Services and Provider Agency Qualifications Currently:

Certified Home Health Agency (CHHA), Hospice Organization, or Article 28 Clinic and/or designated through the NYS Children's Provider Designation Review Team

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

➤ *Please see staff qualifications if not a CHHA, Hospice Organization, or Article 28*

[Children's Home and Community Based Services \(HCBS\) Manual \(ny.gov\)](#)

Defining Provider Capacity Statewide

Current Capacity:

- Currently 4 providers with 7 sites are designated for Palliative Care Services
 - Palliative Care Providers are serving 14 counties out of 62 in NYS
 - 143 children are currently receiving at least one service
 - There clearly is a need

Changes in Process:

- Service rates:
 - 25% enhanced rates have been added
 - 5.4% COLA rate enhancement has also been added effective 4/1/22
 - [Children's Consolidated Waiver Services \(HCBS\) Rate Summary \(ny.gov\)](#)
- Staff Qualifications:
 - Adjustments have been added to a current Waiver Amendment awaiting approval

Group Discussion

What is Needed?

- What other Qualifications would be helpful to attract other providers?
- What changes need to happen, if any, regarding the service, type, qualifications, etc.?
- What are challenges related to the provision of these services?
- What would make services better/more accessible?
- What outreach and or education efforts would help?
- What other changes would be helpful?

How can you help?

- Who do you work with in your community who might be interested?

Other Service Strategies

DOH will be hosting Regional Meetings to discuss various topics, including relevant discussions on building provider capacity.

HCBS providers, Health Homes, care management agencies, Medicaid Managed Care Plans, Families, Advocates, and other children's stakeholders will be invited

An announcement will be forthcoming including dates, times, and agenda.

Follow up

- Should the Palliative Care service and capacity discussion continue?
- Would this group like to continue to meet and discuss how to further collaborate and develop ways to outreach to build capacity?
- Would the group like to fold further discussion into the Regional discussions?
 - If so, this group could meet again after those discussions to determine what else is needed
- Further ideas how to move forward to next steps?

We encourage all participants and relevant stakeholders to reach out to the BH.Transition@Health.ny.gov with additional questions and/or any follow up requests and suggestions

Appendix

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Children's HCBS Overview

- All children and youth eligible for Children's Waiver under 1915(c) authority in New York State may receive a range of Home and Community Based Services (HCBS) based on their individual needs.
- HCBS was designed to allow children and youth to participate in developmentally and culturally appropriate services.
- HCBS are designed for children and youth who, if not receiving these services, would be at risk for a level of care provided in a more restrictive environment, such as a long-term care facility or psychiatric inpatient care.
- The new consolidated Children's Waiver serves four target populations for children/youth:
 1. Serious Emotional Disturbance (SED)
 2. Medically Fragile (MedF)
 3. Developmental Disability (IDD) and Medically Fragile
 4. Developmental Disability (IDD) and in Foster Care

Children's Waiver Eligibility and Referrals

- Children/youth must meet Level of Care (LOC) functional criteria and suffer from the symptoms and stress of chronic conditions or life-threatening or terminal illnesses.
- Health Home care managers (HHCM), for children/youth with Medicaid; or Children and Youth Evaluation Services (C-YES); for children/youth without Medicaid; conduct the Level of Care (LOC) eligibility determination for the Children's Waiver
- HHCM or C-YES develops a Plan of Care with the eligible member, their family, and identified supports regarding the needs/goals they want to address and the choice of services and service provider
- HHCM or C-YES then makes referrals to HCBS Children's Waiver designated service providers

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.
- Qualifications: Child Life Specialist with certification through the Child Life Council; Creative Arts Therapist licensed by the State of New York; Music Therapist with a Bachelor's Degree from a program recognized by the NYS Education Department; Play Therapist with a Master's Degree from a program recognized by the New York State Education Department; current Play Therapist Registration conferred by the Association for Play Therapy (Expressive Therapy (Art, Music, and Play))

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.
- Qualifications: Massage therapist currently licensed by the State of New York

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.
- Qualifications: Pediatrician or Family Medicine Physician board certified in Pediatrics or Family Medicine licensed by the State of New York; Nurse Practitioner licensed by the State of New York; Registered Nurse licensed by the State of New York under the direct supervision of a Pediatrician or medical physician, board certified in Pediatrics

***Providers must be an Article 28 Clinic, Hospice Organization or a Certified Home Health Agency to provide this specific service.*

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
- Qualifications: Licensed Clinical Social Worker (LCSW), Licensed Master Social Worker (LMSW), Licensed Psychologist, Licensed Mental Health Counselor (LMHC), or Licensed Creative Arts Therapist (LCAT) that meet current NYS licensing guidelines

Current Designation for Palliative Care Services

- 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 Massage 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