

Working Group to Study Pediatric Hospice Services

**Connecticut General Assembly
Public Health Committee**

**Discussion document for 29 Jan, 2025 Sub-Working
Group**



Working Group to Study Pediatric Hospice Services
29 Jan, 2025 – Topics for Discussion



Working Group to Study Pediatric Hospice Services

CT State Assembly Working Group Mandate



Mandate from CT State Assembly to maintain focus on our deliverable

(b) The working group shall be responsible for the following:

- 1) Reviewing existing hospice services for pediatric patients across the state;
- 2) Making recommendations for appropriate levels of hospice services for pediatric patients across the state; and
- 3) Evaluating payment and funding options for pediatric hospice care.

Requested report date to Assembly

March 1, 2025 (TA Marchione researching)

Working Group to Study Pediatric Hospice Services

Details on the Katie Beckett Waiver Program



What is the Katie Beckett Waiver Program?

- The Katie Waiver Program allows DSS to provide services to individuals 21 years and younger who have a physical and/or co-occurring developmental disability who would normally not qualify for Medicaid due to family income.
- It provides case management rendered by a home health agency in addition to standard Medicaid covered services such as physician services, therapy services, home health services, hospital inpatient and outpatient services.
- It provides home and community-based services to clients who would prefer to reside in their homes or community instead of in an alternative institution.

Is it only for chronically and terminally ill children?

- No, the Katie Beckett waiver does not require children to be terminally or critically ill to be eligible, rather it focuses on whether the child has a disability that necessitates a significant level of care at home.
- We currently do not have data to confirm whether they are chronically, terminally, or critically ill. (Please see question addressing requirements for waiver criteria that children must meet.)

What are the requirements for consideration and is this in place of Medicaid?

- People who have chronic health conditions or disabilities may qualify
- They must meet financial requirements (be financially eligible for Medicaid. (Under this waiver, the income of a parent or spouse is not counted when determining Medicaid eligibility, however it must be listed on the application)
- They must meet the age requirement (21 years or younger)
- They must meet the DSS "Level of Care Requirement". (That is the client would receive services in an institutional setting without the waiver services)
- The Katie Beckett Waiver Program is **not** a replacement for Medicaid, but it is a Medicaid Program.

Do children with no insurance qualify for Medicaid?

- Yes, if they meet eligibility requirements including age and income.



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Guidance from Kerri Padgett, MA Pediatric Palliative Care Network (PPCN)

Recommendations for program success

Palliative Care/Hospice involvement	Connect hospice early in process to socialize services and skills; frequency of involvement will likely change based on child's condition and/or family support needs
Resources	Since there are more patients than services available, it's important to increase practitioner training and share resources where possible
Practitioner Support	Because of potential long-term support needed by patient and family, it's important to help the medical team to manage patient demands and also provide resources to address the emotional impact on practitioners
Team Coordination	It's critical to have an interdisciplinary team supporting each patient and also to work with patient's core medical providers
Managing family needs	Offer ongoing family support at the level they need – care team leader can advise frequency and intensity – don't forget to address the needs of siblings (typically underserved because of limited services)
Language access	Ensure multilingual information for different cultural needs
Starting a program	Starting with pilot is a great way to work through the details and gain consensus with stakeholders as the program emerges (i.e., 'Walk before you run')
Program Champion	Identify a dedicated champion/sponsor (MA has lobbyist) to keep pediatric palliative care and hospice support in the forefront of legislators, the public, the medical community, etc
Family Stories	The strongest way to make a case is to include testimonials & feedback from families in all reporting/messaging to drive home the need with decision makers



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Considerations to create a new program

New program summary (use MA PPCN as model)	Services we should offer	Codify this program as a service	Criteria considerations	Location-specific needs
<ul style="list-style-type: none">•A program that offers comprehensive direct and consultative community-based pediatric palliative care services state-wide through a network of state-licensed hospice programs, and an array of professional and volunteer services	<ul style="list-style-type: none">•Pain and symptom management•Case management and assessment•Social services, counseling, and bereavement services•Volunteer support services•Respite services•Complementary therapies	<ul style="list-style-type: none">•Focus more on it being a service as opposed to palliative vs. hospice to increase family acceptance•Transition from a palliative approach to a hospice approach as the child progresses within their disorder or disease.•Treat all children but determine number of visits based on patient needs or psychosocial needs.	<ul style="list-style-type: none">•A child would fit criteria when diagnosed with a chronic, acute, or terminal illness.•Levels of payment could be determined by number of visits•this would be considered, without saying the words, palliative vs. hospice.	<ul style="list-style-type: none">•In addition to home-based patients, we need to consider children who are sick and dying in hospitals. These children are closer to death and would be put on “hospice”.•This level criteria right now is general inpatient but would need to be routine to help with bereavement and pronouncements.

Working Group to Study Pediatric Hospice Services

Our immediate timeline to meet CT State Assembly expectations



February 2025

March 2025

WG discussions

Confirm deadline for CT Assembly report

Add 2 more sub-group discussions in February?

Build out details and steps

Create draft WG report

Include data, details & program elements

Consult with sub-working group members to clarify & correct as needed

Finalize & socialize report with WG

Gain consensus on elements with WG

Consult with other key stakeholders – socialize themes and recommendations

Present report to CT State Assembly Committee

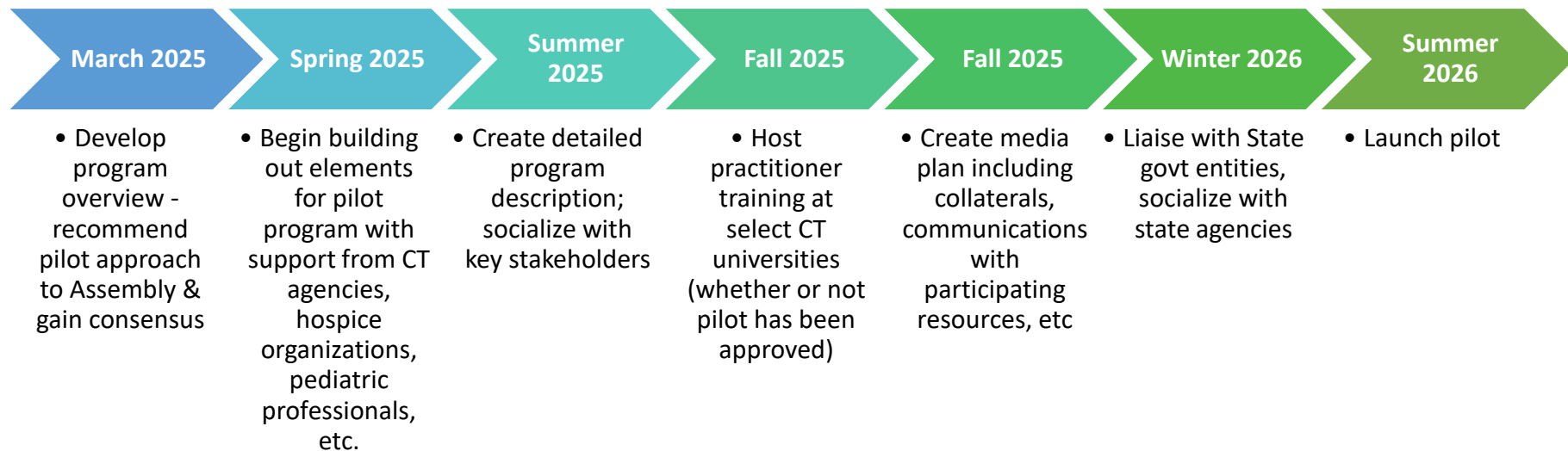
WG Chairs offer overview; WG members offer details as needed

Provide detailed written report with data, descriptions, etc.



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Moving ahead...overview of proposed timeline for pilot



Appendix



- Massachusetts Program as a Model?
- Data from 2020 Massachusetts Study on Parents' Expectations/Needs
- Sample CT Program Brochure
- MA PPCN Program Brochure
- Full mandate / details

Working Group to Study Pediatric Hospice Services Refer to/Use Massachusetts Program as a Model?



Massachusetts' Pediatric Palliative Care Network: successful implementation of a novel state-funded pediatric palliative care program

U.S. children with life-limiting illness face barriers to accessing palliative care. In 2006, Massachusetts signed into law a statute providing for the creation and funding of the Pediatric Palliative Care Network (PPCN).

This innovative, exclusively state-funded program provides comprehensive direct and consultative community-based pediatric palliative care services including:

pain and symptom management

case management and assessment

social services, counseling, and bereavement services

volunteer support services

respite services

complementary therapies

Provision of care is through a network of state-licensed hospice programs, and an array of professional and volunteer services.*

**NOTE: MA health system does not limit services because of the source of payment/funding since most children are covered by MassHealth. This may impact how we deliver a similar program in CT.*

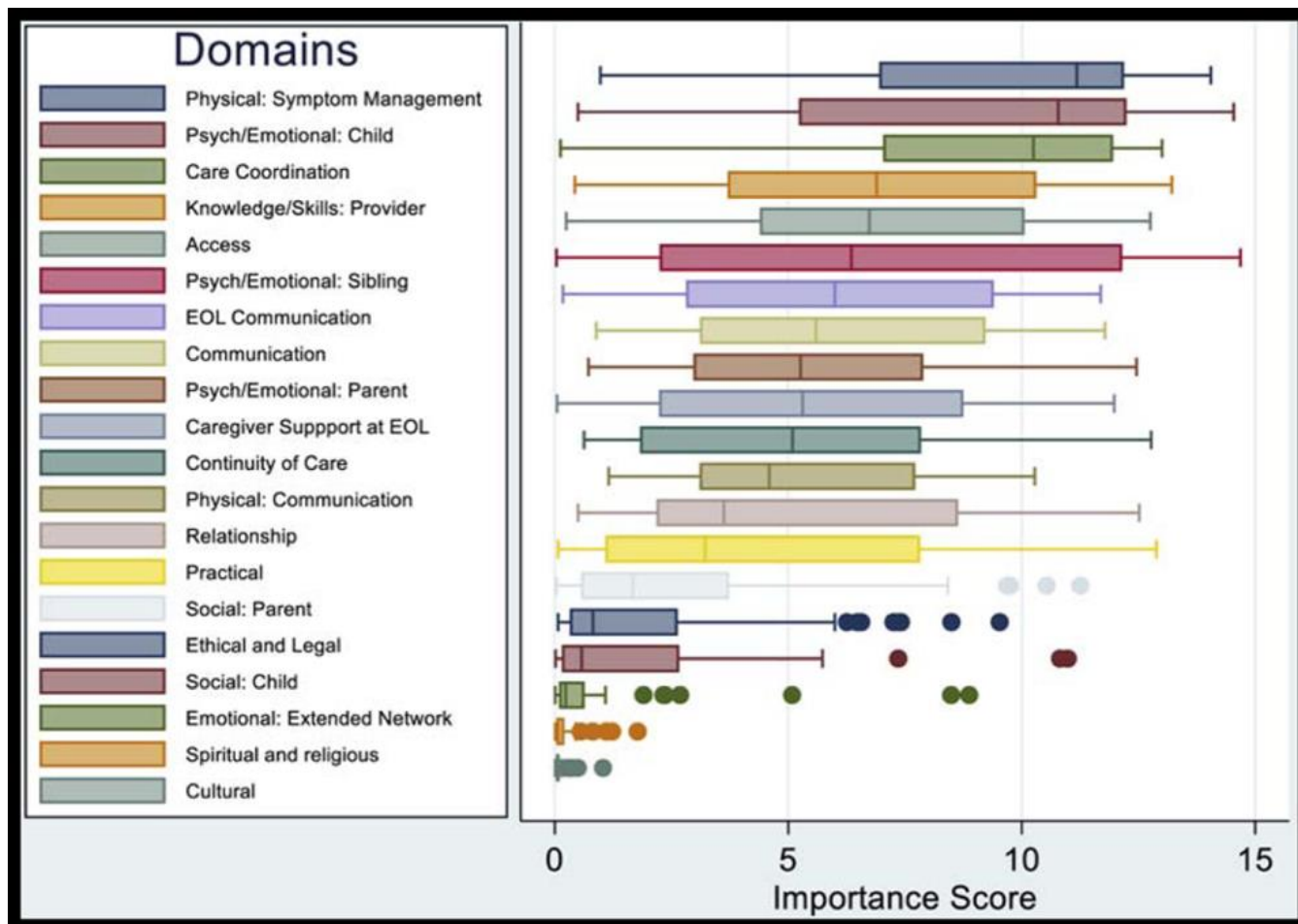
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2020 Massachusetts Study on Parents' expectations/needs



A 2020 MA study asked parents what they valued regarding Pediatric Palliative and Hospice Care in the home setting.

Practitioner coordination, skills and access to services ranked high – just behind children’s physical management and the psychological and emotional needs of the child and their siblings.





Working Group to Study Pediatric Hospice Services PPCN Brochure – example of communications

A network of people caring for children. And their families.



The Pediatric Palliative Care Network



What is palliative care?
Palliative (pah-lee-ee-ee-oh) care is comprehensive treatment of the discomfort, symptoms and stress of serious illness. It is a key part of care for children living with a life-limiting illness and an important source of support for their families. The Pediatric Palliative Care Network seeks to improve the quality of life of the entire family through its support and services.

Is palliative care the same as hospice?
No. Hospice gives care and comfort only at the end of life. Palliative care gives care and comfort through the whole course of a child's disease or illness.

For more information:
1-800-882-1435
617-624-6000
TTY 617-624-5992
Interpreter services available
www.mass.gov/ppcn
palliative.palliative.care@state.ma.us

The Pediatric Palliative Care Network
Massachusetts Department of Public Health
Division for Children & Youth with Special Health Needs
250 Washington Street, 5th Floor
Boston, MA 02108



The Pediatric Palliative Care Network

Serving children living with life-limiting illnesses and their families



The Pediatric Palliative Care Network

"Palliative Care isn't about death. It's about giving an option to what you want. What they can do - what they don't want to do - so you can be sure you're doing the best for your child."



Comfort and care for children with life-limiting illnesses and their families.
Dealing with the diagnosis of a serious illness in a child can be difficult for the entire family. It is important that you, your child, your family, and you get the support and care you need.

The goal of the Pediatric Palliative Care Network is to improve quality of life for your entire family through its support and services.

What services are available?
Palliative care services may include: pain and symptoms management, nursing, assessment and care management, psychiatric and social services, sibling support, volunteer support, respite care, 24 hour nurse on call, complementary therapies such as music, art, massage, and others, and bereavement care if needed. Complementary therapies can be provided if services are readily provided in the home. Your family may choose which services you believe would be most helpful.

How much will care cost?
The services of the Pediatric Palliative Care Network are provided at no cost to eligible children and their families if those services are not already covered by the child's health care plan.

Who is part of the Network?
The Massachusetts Department of Public Health contracts with community-based organizations throughout the state to serve the Pediatric Palliative Care Network. These unique programs are located within focused hospice organizations because these professionals are experienced in helping to improve quality of life and managing symptoms. However, palliative care is not the same as hospice care.

Providers in the Pediatric Palliative Care Network play an important role, including the child, family, physicians, nurses, social workers, counselors, and volunteers.

Will our regular doctor be involved in my child's care?
Yes. Your child's regular doctor and health care team will still care for your child. A child may still receive treatment toward a cure, since new cures may be discovered during his or her lifetime.

Is my child eligible?
A child must be 18 years old or younger and must live in Massachusetts to receive Pediatric Palliative Care Network services. A physician must state that the child has been diagnosed with a condition that could limit medical life expectancy, such as advanced or progressive cancer, major organ failure, LEP, stroke, bleeding, organ system problems, neurological or metabolic disorders, or severe congenital injury. There are no income limits or citizenship requirements.

How can my child be referred to the Network?
Anyone can make a referral. Referrals may be made directly by a family, by a child's physician, nurse, or other health care professional, or by others who work with the family. To find out which organization serves your city or town, call 800-882-1435.

How do I learn more?

- Call the Massachusetts Department of Public Health's Community Support Line at 435-6265, LEP or (714)264-0800. Interpreter services are available.
- Call the Hospice & Palliative Care Education of Massachusetts at 914-555-7671.
- Go to www.mass.gov/ppcn

1-800-882-1435

Palliative care serves the physical, emotional, social and spiritual needs of children living with life-limiting illnesses and their families.



CT Working Group to Study Pediatric Hospice Services

Draft brochure – example of communications

Our Mission
CONNECTICUT CHAMPION Care strives to offer children and families support for their complex health needs, advocacy to find the best solutions, management of their team & palliative care to offer care and comfort.

What is palliative care?
 Palliative care is comprehensive treatment of the discomfort, symptoms and stress of a serious illness. It is a key part of care for children living with life-limiting illness and an important source of support for their families. **CONNECTICUT CHAMPION Care** promotes health, management, advocacy and palliative care for the child and seeks to improve the quality of life for the entire family through its support and services

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CONNECTICUT CHAMPION Care
 Children's Health, Advocacy, Management & Palliative Care

For more information:
 1-800-xxx-xxxx
 860-xxx-xxxx
 TTY 860 xxx xxxxx

Interpreter services are available
www.CT.DPH.ctchampioncare.gov

CONNECTICUT CHAMPION Care
 CT Department of Public Health
 Div of xxxxx xxxxxx
 410 Capital Avenue
 Hartford, CT 06134

CONNECTICUT CHAMPION Care
 Children's Health, Advocacy, Management & Palliative Care

Promoting the well-being of children living with life-threatening conditions and providing support for their families

CONNECTICUT CHAMPION Care
 Children's Health, Advocacy, Management & Palliative Care

"Palliative care is about finding meaning, peace, and comfort in the face of suffering. It is about putting the patient at the center and providing them with the best possible care."
 Dr. Balfour Mount

Patient-centered and family engaged
 U.S. children with life-limiting illnesses face barriers to accessing palliative care. **CONNECTICUT CHAMPION Care** is designed to offer support to children and families so they don't have to face these challenges alone.

What services are available?

- o Pain and symptom management
- o Case management and assessment
- o Social services, counseling, and bereavement services
- o Volunteer support services
- o Respite services
- o Complementary therapies

How much will care cost?
 Services of **CONNECTICUT CHAMPION Care** are provided at no cost to eligible children and their families if these services are not already covered by the child's health care plan.

Who is part of the CONNECTICUT CHAMPION Care network?
 The Connecticut Department of Health contracts with certified community-based organizations throughout the state to form the network of providers. These unique programs are licensed hospice organizations whose professionals are experienced in helping to improve quality of care, manage symptoms and offer services to the child and family. Everyone in the network plays a vital role including the child, the family, physicians, nurses, social workers, counselors and volunteers.

Will our regular doctor be involved in my child's care?
 Yes. Your child's regular doctor and health care team will still care for your child.

Can my child receive curative treatments for their condition?
 A child may still receive treatment for a cure, since new cures may be discovered during his or her lifetime.

Is my child eligible?
 A child must be 18 years old or younger and must live in Connecticut. A physician must state that the child has been diagnosed with a condition that could limit normal life expectancy such as advanced or progressive cancer; major organ failures; HIV; cystic fibrosis; progressive genetic, neurological or metabolic disorders; or severe cerebral palsy. There are no income limits or citizenship requirements.

How can my child be referred to this program?
 Anyone can make a referral. Referrals may be made directly by a family, by a physician, nurse or other health care professional or by others who work with the family. To find out which resources support your area, call 1-800-xxx-xxxx

To learn more
 Call the CT Department of Public Health's **CT CHAMPION Care** support line at 1-800-xxx-xxxx – or - 860-xxx-xxxx
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 Interpreter services are available to help you

Or visit our website:
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CONNECTICUT CHAMPION Care

Children's Health, Advocacy,
Management & Palliative Care



For more information:

1-800-xxx-xxxx

860-xxx-xxxx

TTY 860 xxx xxxx

Interpreter services are available

www.CT.DPH.ctchampioncare.gov

CONNECTICUT CHAMPION Care

CT Department of Public Health

Div of xxxxx xxxxxx

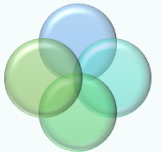
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CONNECTICUT CHAMPION Care

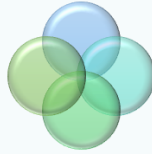
Children's Health, Advocacy,
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Working Group Mandate

CGA/COMMITTEES/PUBLIC HEALTH - Working Group to Study Pediatric Hospice Services - [PA 24-19 Section 29.pdf](#)

- (a) The chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall establish a working group to examine hospice services for pediatric patients across the state.
- (b) The working group shall be responsible for the following: (1) Reviewing existing hospice services for pediatric patients across the state; (2) Making recommendations for appropriate levels of hospice services for pediatric patients across the state; and (3) Evaluating payment and funding options for pediatric hospice care.
- (c) The co-chairpersons of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall schedule the first meeting of the working group, which shall be held not later than sixty days after the effective date of this section.
- (d) The members of the working group shall elect two chairpersons from among the members of the working group.
- (e) The administrative staff of the joint standing committee of the General Assembly having cognizance of matters relating to public health shall serve as administrative staff of the working group.
- (f) Not later than March 1, 2025, the chairpersons of the working group shall report, in accordance with the provisions of section 11-4a of the general statutes, to the joint standing committee of the General Assembly having cognizance of matters relating to public health concerning the findings of the working group.