Working Group to Study Pediatric Palliative Care/Hospice Services

Connecticut General Assembly

Public Health Committee

Discussion document for 11 Feb, 2025 Sub-Working Group

Working Group to Study Pediatric Hospice Services
11 Feb, 2025 – Topics for Discussion

CONNECTICUT GENERAL ASSEMBLY

- Synopsis & themes from 29 Jan Sub-Working Group meeting
- DPH Survey results
- Child-centric service model
- Key elements from CA, MA, VT programs to consider
- Next steps/draft timing for Working Group report

Working Group to Study Pediatric Hospice Services

Themes from 29 Jan meeting - recap

Ensure that this solution is a child-centered service run by the State of Connecticut

- All services and resources radiate from the child and family needs
- Integrate components from CA, MA and VT programs

DPH team to pursue survey results to incorporate into Assembly report.

- Data will be key to emphasizing the importance of this service to all children
- Belief that there is a much larger under-served population that will need skilled caregivers

Pursue an optimal solution with Assembly

- Emphasize coordination across state agencies, pediatric medical professionals, medical facilities to ensure seamless delivery
- Offer home-based care in additional to facility-based services
- Emphasize the importance of early intervention with hospice/palliative care professionals to help support families
- Address importance of developing medical practitioners (esp. RNs) with CT university/medical facility programs to provide skilled services
- Emphasize that pediatric services include palliative/hospice AND concurrent care

Analyze gaps and barriers for report

- Coordinate & leverage skilled staffing across geographic areas
- Funding – suggesting centralized state payment system, coordinate with existing sources (eg, private insurances, Katie Beckett Waiver program, Medicaid, etc)
- Identify/partner with existing Hospice organizations, medical programs, providers
- Expand Workforce training to develop experienced pediatric resources
- Regulatory oversight/coordination needed
- Codify pediatric hospice provider certification requirements
- Identify and coordinate Insurance sources
- Education needed for medical professionals, children’s services, community organizations, families

Confirm program champions

- Assembly sponsor to lead this effort
- Lobbyist to keep need at the forefront

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DPH Survey results to support development of dedicated program

Debrief on DPH survey results from Barbara Cass

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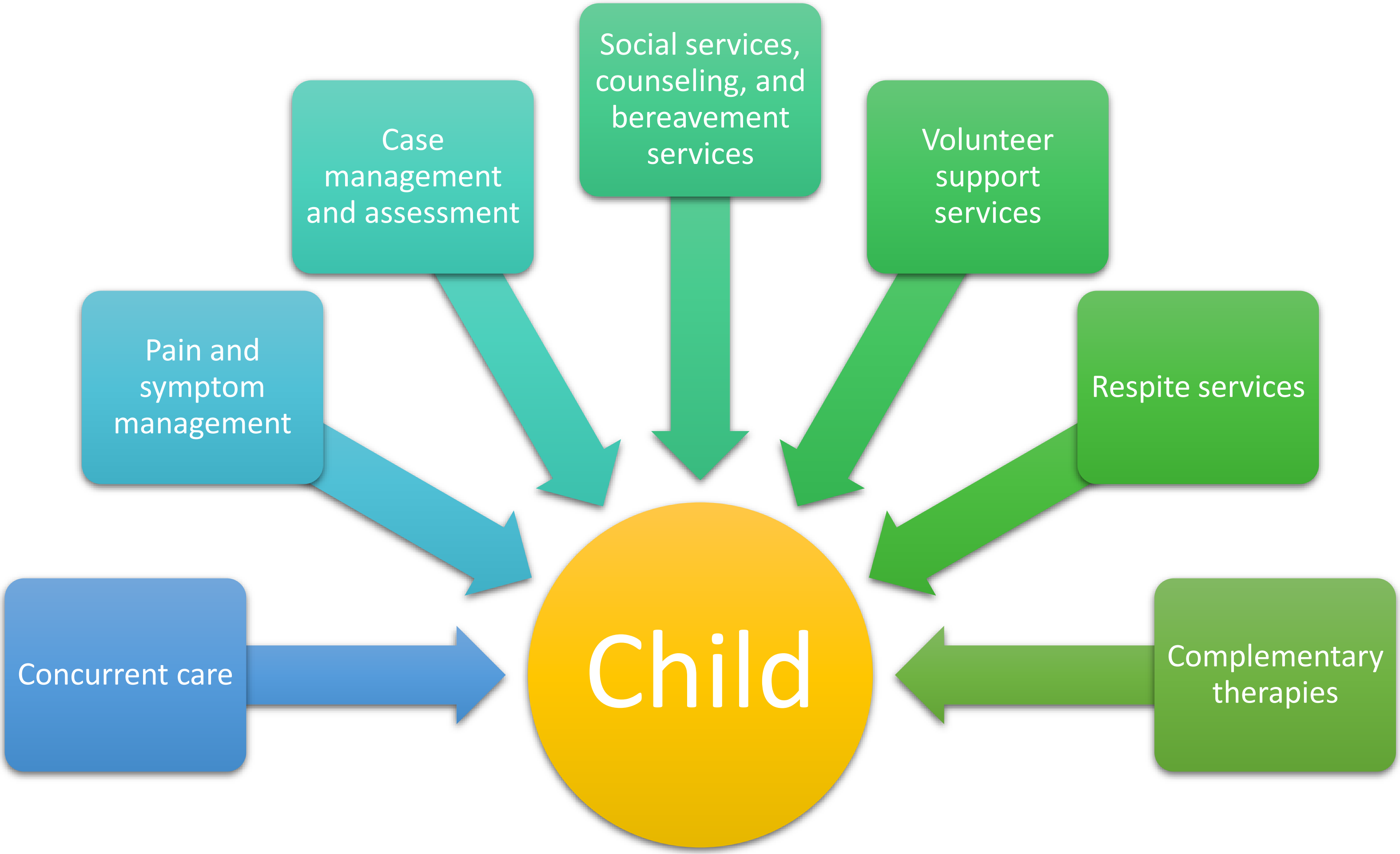
State of Connecticut Child-centric service model that supports child and family needs



Concurrent care

Pain and symptom management

Case management and assessment

Social services, counseling, and bereavement services

Volunteer support services

Respite services

Complementary therapies

Child

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Working Group to Study Pediatric Hospice Services
Synopsis from CA, MA, VT programs *(details found in Appendix)*

"Palliative care can provide relief from symptoms, improve satisfaction and outcomes, and help address critical needs during difficult times — all outcomes of great benefit to children living with serious illness and their families. As these three states illustrate, state Title V CYSHCN and Medicaid programs play important roles in improving the access of children with serious illness and their families to palliative care services."

State of California

- The California Medicaid program (Medi-Cal) pays for palliative care services provided to both children and adults and oversees managed care organizations' provision of the services. The California Children's Services (CCS) program pays for palliative care services provided to select CYSHCN.
- ***Covered services:***
  - Advance care planning
  - Palliative care assessment and consultation
  - Pain and symptom management
  - Plan of care
  - Care coordination
  - Mental health and medical social services
  - Palliative care team consultation

Commonwealth of Massachusetts

- The Massachusetts Title V CYSHCN program operates the pediatric palliative care program, pays for palliative care services, conducts outreach to families and referring providers, and engages families in service delivery and program design.
- ***Covered services:***
  - Pain and symptom management
  - Nursing
  - Assessment and case management
  - Spiritual care
  - Social services
  - Sibling support
  - Volunteer support
  - Respite care
  - 24-hour nurse on call
  - Complementary therapies such as music, art, massage, and others
  - Bereavement care if needed

State of Vermont

- Vermont Medicaid funds program administration and pays for palliative care services authorized by the state's Title V CYSHCN program. Title V administers the program, fills gaps in program coverage, and coordinates with other initiatives to enhance access to palliative care services for Vermonters of all ages.
- ***Covered services:***
  - Care coordination
  - Family training
  - Expressive therapy
  - Skilled respite
  - Family grief counseling/bereavement counseling

Information taken from National Academy for State Health Policy (NASHP) website: https://nashp.org/three-state-snapshots-of-pediatric-palliative-care-california-massachusetts-and-vermont/

Working Group to Study Pediatric Hospice Services
Report development, consultations, next steps – *Draft timeline

Feb 12	Feb 18	Feb 22	Feb 26	Feb 27	Feb 28	Mar ??
Report development	Report shared with sub-working group; WG reviews, suggests edits, report updated	Detailed consultation with Assembly champions & lobbyist; draft report modified to reflect feedback	Revised draft shared with sub-working group for inputs/final edits	Final report shared with full working group	Final draft shared with Assembly champions & lobbyist	Report delivered to CT State Assembly

**Timeline assumes Mar 1 report to CT State Assembly*

Appendix

- Recommendations for success (Kerrie Padgett, MA PPCN)
- Elements of Katie Beckett Waiver Program
- Details on programs in CA, MA, VT
- Sample CT Program Brochure
- Working Group – CT State Assembly mandate

Working Group to Study Pediatric Hospice Services

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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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
- The 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 quality for Medicaid?

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

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State of California – Pediatric Palliative Care Waiver Program

California Medicaid Pediatric Palliative Care Coverage Policies, 2024

Children's clinical eligibility criteria	•Medicaid members of all ages who meet diagnosis-specific criteria established by the Medicaid agency •Members under age 21 and have a life-threatening diagnosis, as defined by the Medicaid agency
Provider qualifications	**MCO**: Each MCO establishes its own requirements but must use "qualified providers for palliative care based on the setting and needs of a member." **FFS**: Medicaid providers, including hospice agencies that are licensed to provide palliative care
Covered services	•Advance care planning •Palliative care assessment and consultation •Pain and symptom management •Plan of care •Care coordination •Mental health and medical social services •Palliative care team consultation
Payment model	**MCO**: Each MCO negotiates payment model and amount with providers. **FFS**: Providers are paid per service for providing palliative care services.

In addition, CCS, which receives Title V funding, will pay for palliative care for children participating in the CCS program who do not qualify for Medicaid. CCS will only pay for palliative services for these children if the palliative care is related to the condition that qualifies a child to participate in the CCS program and if the services are part of a child's approved plan of care. The program will pay CCS-paneled physicians, hospice agencies, and home health agencies for the same services as the Medicaid program. CCS is funded through state, county, and federal funds, including Title V.

Details taken from National Academy for State Health Policy (NASHP) website: https://nashp.org/three-state-snapshots-of-pediatric-palliative-care-california-massachusetts-and-vermont/

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Commonwealth of Massachusetts – Pediatric Palliative Care Network

Massachusetts Department of Public Health Pediatric Palliative Care Coverage Policies, 2024

Children's clinical eligibility criteria	Children under age 22 with life-limiting diagnosis whose health plan does not cover palliative care services
Provider qualifications	Hospice providers that are selected via a procurement process and meet the standards[2] established by the Department of Public Health. Among other things these address provider training and experience, program staffing, and delivery of care.
Covered services	•Pain and symptom management •Nursing •Assessment and case management •Spiritual care •Social services •Sibling support •Volunteer support •Respite care •24-hour nurse on call •Complementary therapies such as music, art, massage, and others •Bereavement care if needed
Payment model	Providers are paid on a cost-reimbursement basis

The PPCN program leverages its contractors for outreach to families and potential referring providers. The standards developed by DPH require PPCN providers to "identify 1–2 community and service providers every year who do not know about PPCN or who are seeking information on pediatric palliative care. The PPCN program should then arrange for a presentation about PPCN." The standards also require contractors to "support and reflect the guiding principles of the Massachusetts Family Engagement Framework," which provides for extensive family engagement at both the individual and program levels. Additionally, DPH has produced videos featuring families served by the program. Finally, PPCN is establishing a statewide family advisory council to "inform program priorities and provide input on discrete projects," ensuring that family input has an impact at both the program and local vendor levels.

Details taken from National Academy for State Health Policy (NASHP) website: https://nashp.org/three-state-snapshots-of-pediatric-palliative-care-california-massachusetts-and-vermont/

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State of Vermont – Pediatric Palliative Care Coverage

Vermont Medicaid Pediatric Palliative Care Coverage Policies, 2024

Children's clinical eligibility criteria	Medicaid beneficiaries under age 21 who are diagnosed with life-limiting illness that is expected to be terminal before adulthood (age 21)
Provider qualifications	Home health agencies that have met Medicaid's requirements for care delivery and training, which include pediatric palliative care training and delivering a broad range of services via an interdisciplinary team. Agencies are required to engage in quality improvement activities as needed to improve program outcomes. There are also required qualifications for specific service providers (e.g., therapy providers).
Covered services	•Care coordination •Family training •Expressive therapy •Skilled respite •Family grief counseling/bereavement counseling
Payment model	Providers are paid per service for providing palliative care services. Most services are billed in 15-minute units.

In addition to their role in development and operation of the PPCP, Title V PPCP staff are engaged in broader efforts to facilitate access to palliative care in Vermont. For example, PPCP staff educate providers who are not PPCP providers about pediatric palliative care through initiatives such as a statewide provider education day. Title V staff have also participated in Vermont's Palliative Care and Pain Management Task Force since 2013. The task force was formed by the invitation of the Vermont legislature to coordinate palliative care initiatives and enhance access to palliative care in Vermont. Each year it prepares a legislative report, including recommendations for improving access.

Details taken from National Academy for State Health Policy (NASHP) website: *https://nashp.org/three-state-snapshots-of-pediatric-palliative-care-california-massachusetts-and-vermont/*

CT Working Group to Study Pediatric Hospice Services

Sample 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

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 along the course of a child's disease or illness.

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
410 Capital Avenue
Hartford, CT 06134

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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

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?

- Pain and symptom management
- Case management and assessment
- Social services, counseling, and bereavement services
- Volunteer support services
- Respite services
- 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.

> *"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

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
TTY users can call 860-xxx-xxxx
Interpreter services are available to help you

Or visit our website:
www.CT.DPH.ctchampioncare.gov

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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.

Working Group meetings can be found on the Public Health Committee YouTube Channel: https://www.cga.ct.gov/ytph