Working Group to Study Pediatric Palliative Care/Hospice Services

Proposed CT Pediatric Program: Overview for the Full Working Group

Feb 25, 2025

Connecticut General Assembly | Public Health Committee

Setting the stage

- Our mandate from the CT State Assembly/Working Group Activities
- Differentiating children’s pediatric palliative/hospice care
- Status of pediatric palliative/hospice care in CT

A reminder of our mandate

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

(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.**

Working Group Activities

- Between September 2024 and March 2025, the Working Group to Study Pediatric Hospice Services met 9 times in core- and sub-working group forums to identify key challenges, share data, expertise and intelligence about issues pertaining to pediatric palliative care and hospice needs
- Pediatric sources were surveyed to assess patient numbers and resources needs, other non-Connecticut agencies with pediatric programs were solicited for their best practices, and working group members identified key challenges to serving children's palliative & hospice care needs
- A proposal for a new model and a phased approach to develop and launch this program has been created
- This presentation provides an overview for a recommendation to the Connecticut General Assembly for their consideration; more research and details will be required to implement this proposed program

Differentiating Children’s Pediatric Palliative/Hospice Care

Under a provision in the Affordable Care Act, concurrent care is an option for children, teens, and young adults up to age 21

Pediatric Hospice

- Specialized medical treatments, curative therapies and concurrent care **can be continued**
- Traditional hospice palliative care is offered **in combination with** other medical treatments and services

Adult Hospice

- Curative measures and specialized medical treatments **are discontinued**
- Traditional hospice palliative care and end-of- life support is offered

Unlike adult hospice patients, pediatric patients can continue any and all curative therapies at the same time as hospice care.

There’s no need to choose between comfort and curative measures.

CONNECTICUT GENERAL ASSEMBLY

Status of Pediatric Hospice Services in the State of CT

Children in the State of Connecticut are in need of pediatric health, palliative care and hospice services but funding to support this need, availability of trained resources along with a delivery framework is extremely limited

Numbers tell the story:

7,800 …how many children in Connecticut with complex medical conditions that limit their life expectancy*

295 …the number of reported children's deaths in our state^

<1 yr=145; 1-14 yrs=57; 15-19 yrs=93

7,800 …how many children with life-limiting conditions who were in need of palliative & hospice care and who would benefit from a comprehensive, coordinated program

Data from 2020 sources:

*National Survey of Children's Health (NSCH). (2019-2020). The National Survey of Children's Health. https://www.childhealthdata.org/learn-about-the-nsch/NSCH - and - PedEOL Care Research Group. (2023, March 10). Fact sheet: Connecticut: Sick kids [Infographic].

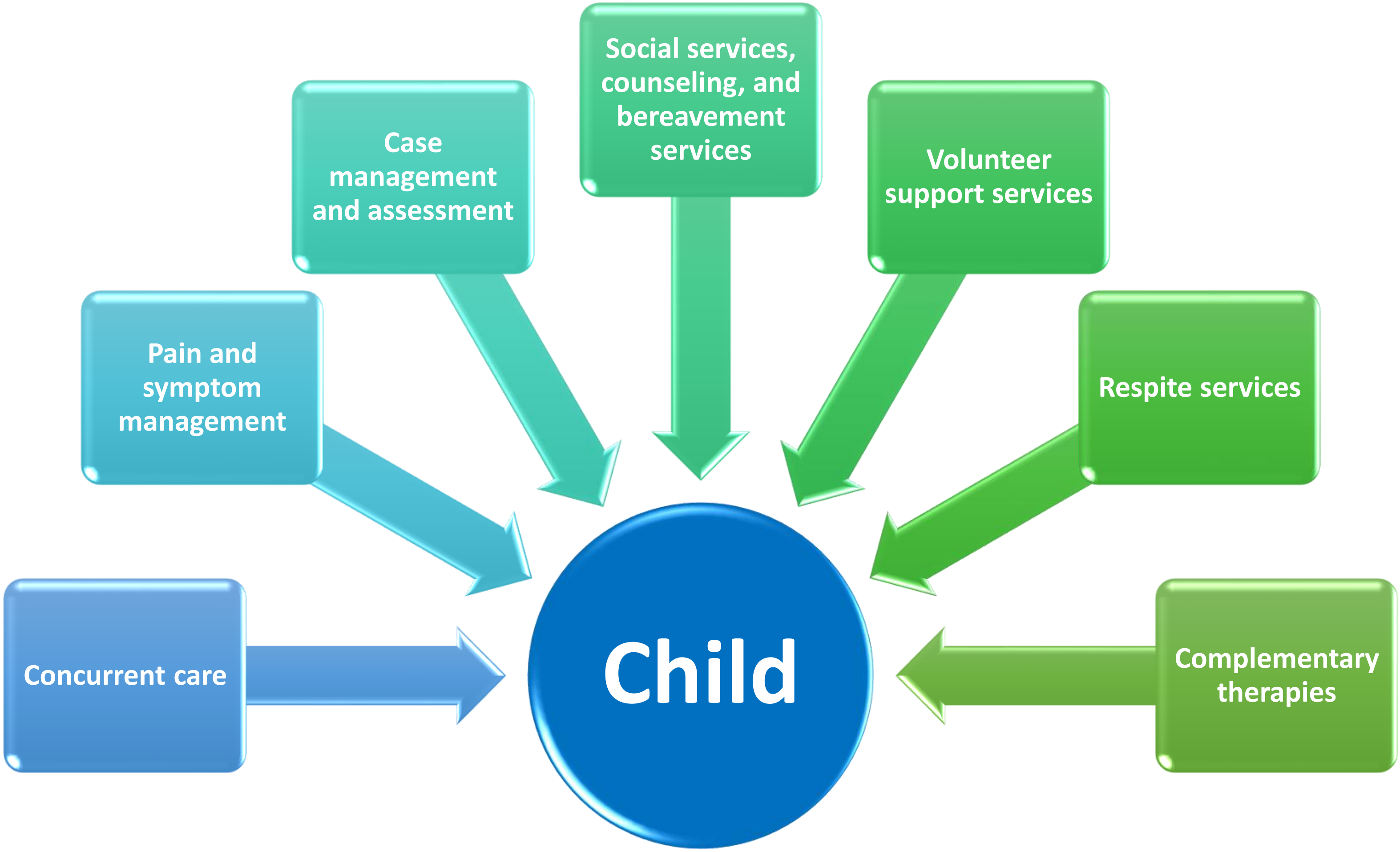
^2020 CDC Wonder data; CDC WONDER

A new approach

- Create a child-centric service model
- An opportunity for change: A best-in-class solution
- New solution: opportunities and gaps
- Comparable programs in the US
- MA study on parents’ priorities

Goal: Create a program in CT that focuses on the child and the family needs
A child-centric service model

CONNECTICUT GENERAL ASSEMBLY



Concurrent care

Pain and symptom management

Case management and assessment

Social services, counseling, and bereavement services

Volunteer support services

Respite services

Complementary therapies

Child

An opportunity for change: Best-in-class solution

Proposal for a new program providing Pediatric Palliative & Hospice Care

CT CHAMPION Care

**Children's Health, Advocacy,
Management & Palliative Care**

Our Mission: To offer children with life-limiting diagnosis and their families services and support for their complex health needs, advocacy to find the best solutions, collaborative management of their provider team, and delivery of concurrent, palliative and hospice care.

CT Champion Care will deliver a child-centric platform of services and resources to children under age 22 with life-limiting diagnosis and their families. Services offered to children and their families will include:

- concurrent care
- pain and symptom management
- case management and assessment
- social services, counseling, and bereavement services
- volunteer support services
- respite services
- complementary therapies

This program will offer a fully-integrated team of skilled practitioners who will partner with the child's primary care providers and offer a tiered approach to the service needs of the child and the family. CT Champion Care will be the central platform that coordinates and delivers palliative/hospice care services to children across the state of Connecticut.

Under a provision in the ACA, this program will allow concurrent care to continue but will deploy comprehensive services to support the child and family as the child's complex needs evolve.

Under this proposal, palliative/hospice practitioners will meet the standards of licensing and training required to support pediatric palliative and hospice needs. Funding will be coordinated at the state level while services will be coordinated and delivered based on the child's geographic location. A central database of skilled practitioners and licensed facilities will be managed at the state level.

This program will offer a best-in-class approach that offers a child-centric health focus, bringing skilled resources together to support the needs of the child and family.

Developing a new solution to pediatric concurrent, palliative & hospice care

Enhanced services opportunities and current gaps

Opportunities that this program offers

- A focus on the child and family
- Ensures delivery of concurrent care, palliative/hospice care and other nursing needs
- Creates a collaborative team to support the broad needs of the child and family
- Addresses both medical and supportive care needs
- Increases the number of skilled pediatric hospice practitioners in CT
- Creates certification and licensure requirements for pediatric hospice
- Offers home-based care in additional to facility-based services
- Provides early intervention by hospice/palliative care professionals
- State-led advocacy to care for our most precious resources (and our most fragile population)

Gaps to be addressed

- State-sponsored funding (especially in light of potential changes in federal funding and/or federal resource availability)
- State-level program oversight and insurances coordination
- Expanding workforce training to develop experienced pediatric resources
- Identification, coordination & leverage of skilled staffing across geographic areas
- Regulatory oversight and coordination
- Codification of pediatric hospice provider certifications/requirements
- Communications & education for medical professionals, children’s service providers, community organizations, & families

Comparable programs in the US to consider as models
Synopsis from CA, MA, VT & WA 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

Washington State

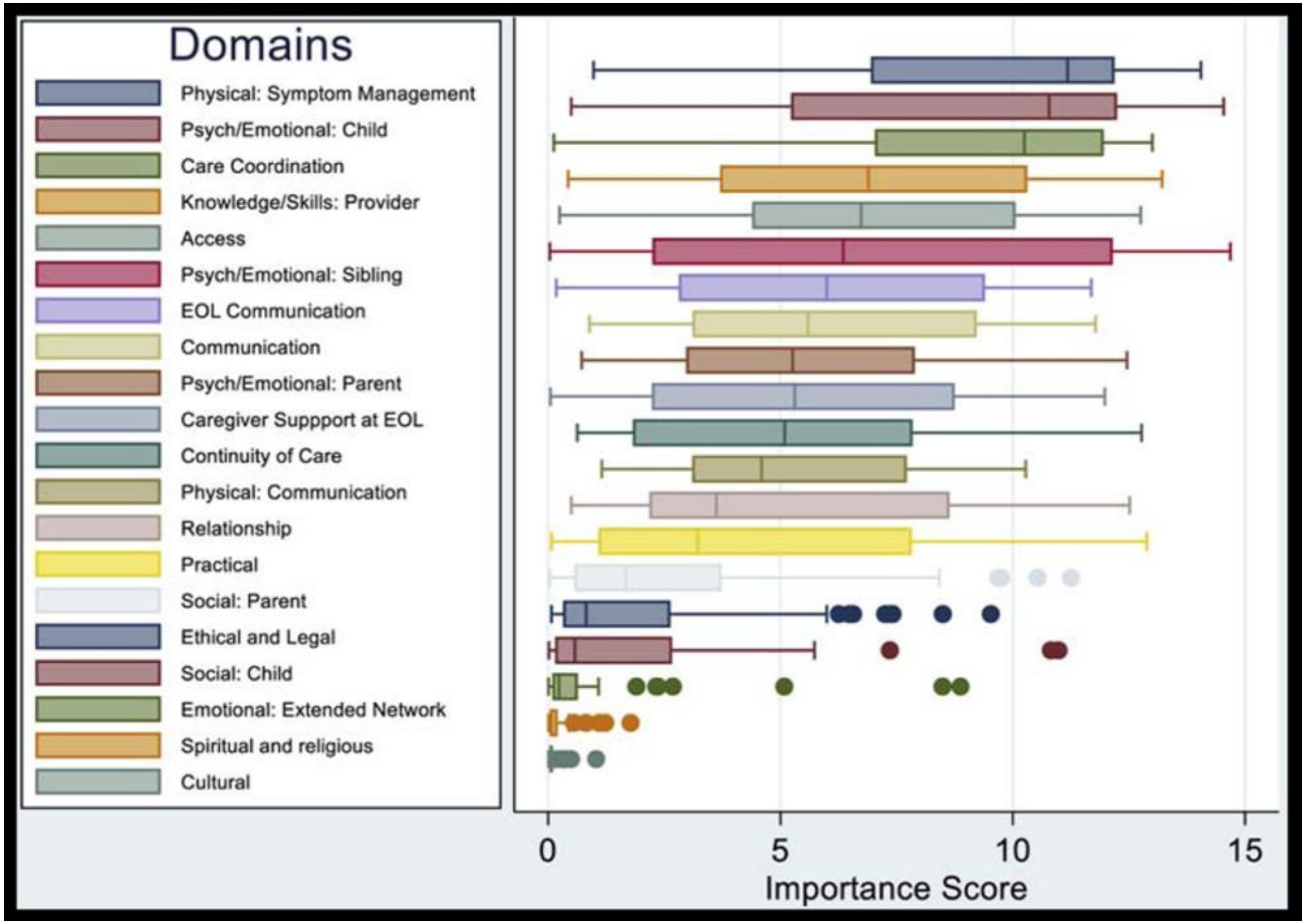
- Washington State created a comprehensive website to reflect the depth and complexity of their residents and their palliative care needs. As such, the Washington Rural Palliative Care Initiative (WRPCI) was established to better serve patients with serious illness in rural communities. This public-private partnership is led by the Washington State Office of Rural Health at the state Department of Health involving over 24 organizations. This work aims to assist rural health systems and communities to integrate palliative care in multiple settings.

- ***Covered services:***
  - Emergency department
  - Skilled rehabilitation
  - Hospice Services
  - Long-term Care
  - Inpatient services
  - Home Health care
  - Primary care

Key family themes for palliative/hospice care in the home setting
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.



Next steps

- A focus on quality: Create a Center of Excellence (CoE) Pilot
- Consider a program ‘soft launch’ through a pilot
- Key CoE Elements: Pilot program partnership
- Recommendations for program success
- Next steps to advance program proposal
- Working group discussion

Focusing on Quality

Center of Excellence (CoE) Value Proposition

Definition of a Center of Excellence

- A center of excellence is a team, a shared facility or an entity that provides leadership, best practices, research, support, or training for a focus area.

What can a Center of Excellence offer? A CoE…

…Serves as an enabler for transformation; acts as a change agent

…Provides collaboration, knowledge sharing, & training; facilitates a community of awareness

…Establishes gates and guardrails, creates policies and governance, develops tools, techniques & best practices

Soft launch considerations

Consider a CT Champion Care pilot program

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Pilot elements:

Program Framework	• Propose that Regional Hospice of Western CT to serve as pediatric & palliative care pilot agency
Program Infrastructure	• Identify resources for program coordination & technology support
RN Training & Education	• Implement customized coursework for RNs through Fairfield University EGAN School of Nursing to expand workforce
State agency collaboration	• Connect DPH resources to pilot program efforts
Define service provider requirements	• Codify certification and licensure requirements for participating agencies & organizations as pilot matures
Medical community connections	• Solicit input from pediatric professionals about needs to help them broaden their capacity

Pilot Program Partnership
Regional Hospice of Western CT and Fairfield University EGAN School of Nursing

Early pilot program efforts will be coordinated by Regional Hospice of Western CT with pediatric palliative & hospice care RN education being developed and delivered by Fairfield University EGAN School of Nursing

Regional Hospice of Western CT

- Serve pediatric patients in the Fairfield County area
- Provide outreach to local pediatricians, medical specialists, other facilities to introduce & coordinate services
- Collaborating with Working Group team, begin to formulate framework & details for a formal program to be expanded state-wide
- Coordinate RN training with Fairfield University EGAN School of Nursing to utilize curriculum and coordinate RN resources for pediatric hospice needs

Fairfield University EGAN School of Nursing

- Collaborate with Regional Hospice and Working Group to define and deliver pediatric training for RNs
- Build competencies for RNs to meet pediatric palliative & hospice care needs and continue to refine curriculum as pilot matures
- Contribute to pilot program elements to ensure RN skills reflect patient needs

Guidance from Kerri Padgett, Massachusetts 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 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

Timeline for our report to the CT State Assembly

Next steps to advance program proposal

Today's Discussion

- Full Working Group consultation and feedback on the proposed program parameters and feedback integrated into final report to Assembly

First week of March

- Final program proposal shared with key stakeholders on behalf of Connecticut State Assembly for consideration

Questions, challenges, ideas
Working group discussion