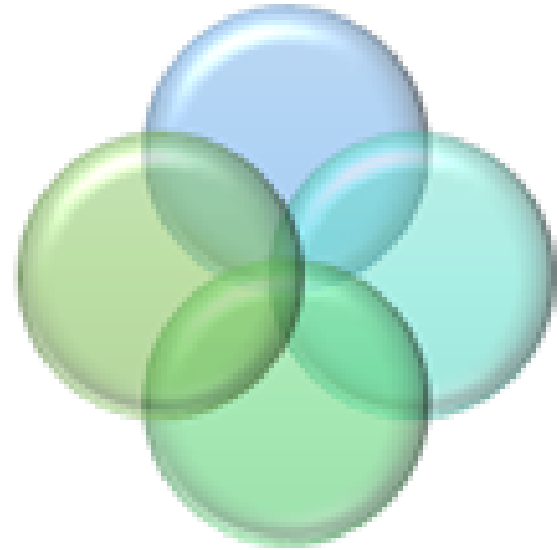


CHAMPION Care

Action Team

Wednesday, 19 November 2025



Today's Discussion

- Welcome
- Today's Themes: Nursing, Insurance Coverage
- Upcoming Meeting Schedule and Action Steps



Nursing

- Education, resources, pediatric palliative/hospice training, pay for shift nurses

Insurance Coverage

- Medicaid vs Private Payers, Katie Beckett Waiver & impact



Nursing

Changes to meet our children's needs

Our state falls short of the much needed and skilled resources to support both facility- and home-based support. This list reflects the most urgent gaps.

Nurses Training

- Formalize/recognize nurses' training with Fairfield Univ EGAN School of Nursing
- Consider tuition/loan payment as an incentive for nurses and APRNs to go into pediatric hospice and hospice in general

Curriculum requirements

- Nursing programs now must include Palliative/EOL in curriculum

Practicum experience

- The concept of a Center of Excellence for Regional Hospice to be a teaching site for rotations for nursing an APRN



Insurance coverage

How to support children's health needs

Private payer sources may be sufficient for some families but others depend upon Medicaid to offer critical care needs

Increasing the Katie Beckett Waiver Cap / Increasing DSS Funds

- Directing the need for increasing the number of recipients on the Katie Beckett Waiver would require either legislative action to authorize DSS to serve more children or converting the program into a state plan amendment (entitlement), which would get rid of the waitlist. It appears that CT has been researching this option.
- Assuming that federal grants (such as Title V block grants) are not a viable option right now, I believe that increasing DSS funds would require lobbying the legislature, unless DSS is willing and able to set aside funds out of its current budget.

Insurance Coverage Mandate for Private Payors

- A mandate for payors to follow Medicaid coverage for hospice and concurrent care would require new legislation

The challenge of navigating support networks/finding solutions to care for a child

Example from the state of Michigan's Concurrent and Hospice Services



This table shows the different sources of services and care. Without receiving the full suite of these services, a child's health can be severely compromised. **By committing to combining concurrent, palliative, & hospice services through a centralized coalition of services, we would reduce the complexity of 'services navigation' for parents and would likely improve a child's longevity and quality of life.**

	Treatment	Hospice Service	Concurrent Curative Service	Both Hospice & Concurrent Curative Services
Pain/Symptom Management	Narcotics, Analgesics	X		
	Antiemetics	X		
Nutrition	Tube Feeding			X
	Intravenous (IV) Fluids		X	
	Total Parenteral Nutrition (TPN)		X	
Respiratory Support	Oxygen	X		
	Bilevel Positive Airway Pressure (BiPAP)			X
	Continuous Positive Airway Pressure (CPAP)			X
	Ventilator		X	
	Respiratory Vests			X
	Cough Assist Device(s)			X
Pharmacy	Antibiotics	X		
	Chemotherapy		X	
	Intravenous immunoglobulin		X	
	Blood products		X	
Supports	Spiritual Support	X		
	Psychological/Social Support	X		
	Bereavement Support	X		
Radiation			X	
Durable Medical Equipment (DME)	Specialized Seating		X	
	Wheelchairs	X		

UPDATE TABLE TO REFLECT CT INFORMATION

Today's Discussion

Questions, Comments, Recommendations



Upcoming Meetings

(Calendar Invitations & Links Forthcoming)

Action Team	Advisory Group	Feb 6, 2026
NOV <ul style="list-style-type: none">• 11/19 DEC <ul style="list-style-type: none">• 12/3 - 1-2 p• 12/10 – 1-2 p JAN <ul style="list-style-type: none">• 1/7 - 1-2 p<ul style="list-style-type: none">○ <i>In person meeting to edit Assembly proposal</i>• 1/21 - 1-2 p<ul style="list-style-type: none">○ <i>Review of updated Assembly proposal</i> FEB <ul style="list-style-type: none">• 2/4 - 1-2 p<ul style="list-style-type: none">○ <i>Final comments before Assembly submission</i>	DEC <ul style="list-style-type: none">• 12/17 - 1– 2:30 p JAN <ul style="list-style-type: none">• 1/28 - 1– 2:30 p<ul style="list-style-type: none">○ <i>Themes for proposal reviewed with Advisory Group</i>	<ul style="list-style-type: none">• Final proposal is due to the CT Assembly by Friday, Feb 6, 2026 