

State of Connecticut
GENERAL ASSEMBLY



PUBLIC HEALTH COMMITTEE
LEGISLATIVE OFFICE BUILDING HARTFORD,
CT 06106-1591

Subgroup of the Working Group to Study Pediatric Hospice Services

Meeting Summary

Wednesday, January 8, 2025

2:30 PM on Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by ToniAnn Marchione at 2:32 PM.
- Attendance: ToniAnn Marchione, Dr. Kerry Moss, Dr. Ross Albert, Barbara Cass, Karen Garlie, Jazmin Johnson, Regina Owusu
- Guests: Melissa Witthoft, Brian Cournoyer

II. Summary of Meetings to Date

III. Begin Establishing Recommendations.

- ToniAnn Marchione explained that the presentation was created by Melissa Witthoft and believes that every recommendation should be on the table. She shared that Melissa Witthoft could make a flow map of the recommendations which will help in finding barriers and solutions. She asked Kerry Moss if a child presents with an end-of-life illness, where do they go from there.
- Kerry Moss gave an example of a teenage patient who has presented with a

brain tumor and explained the process of how such a case is handled.

- ToniAnn Marchione understands that a patient starts with a homecare perspective, and she asked if they would get palliative care on top of that.
- Kerry Moss responded that their hope would be that the palliative care is the patient's service provider and having a contact in the home is important as an aid to deliver services.
- ToniAnn Marchione commented that palliative care currently is inconsistent with visits and stated that they need some form of consistent nursing in the home.
- Kerry Moss agrees with having some form of consistent nursing in the home. She is comfortable with the patient at home and would need eyes and ears as well as the capability for medications and support.
- ToniAnn Marchione asked if traditional homecare offers PT and other support services.
- Kerry Moss answered that traditional homecare does not always guarantee in-home PT.
- Jazmin Johnson asked if the patient is on Medicaid insurance.
- Kerry Moss responded that she is currently on private insurance.
- Jazmin Johnson stated that a lot of what the patient needs to settle in home care can already be taken care of by private insurance. She believes that the barrier is finding an agency that is willing to provide pediatrics in the home.
- Kerry Moss agrees that is the most obvious barrier.
- Jazmin Johnson stated that she can see commercial payers acting differently as they may not cover PT or DME.
- Barbara Cass stated that she looked at data and found out that there are fourteen pediatric certified palliative or hospice care nurses in the State. She added that there is a shortage of staff in general for palliative and hospice care. She asked how many providers identify as offering this service and who has capacity at any given time.
- ToniAnn Marchione stated that Regional Hospice would like to become a center to train staff or to start a program to train. She also asked Kerry Moss if they removed the criteria of six months or less for pediatric hospice to tell a guardian that their dependent will be dead in six months or less. She also

asked if it would be beneficial to sign up this individual for a hospice- like program at this point.

- Kerry Moss commented that the six months criteria for hospice could be a bigger challenge to providers and removing that criteria will allow providers to recommend a hospice model of care. She stated that they usually don't talk about the six-month designation with families and that the major misconception is that hospice is seen as giving up hope. She believes that merging palliative and hospice care will yield more positive responses from families.
- Melissa Witthoft asked if they removed the word hospice from the dialogue with families would it change parental involvement.
- Kerry Moss answered that the result would depend on how it is done and stated that the word hospice does change a lot. She believes the limitation is families accepting hospice at a time when hospice care is most appropriate.
- Melissa Witthoft stated that she understands the value of hospice and was brainstorming the what if.
- Barbara Cass stated that she has heard three recommendations:
- (1) creating a center of excellence for training; (2) developing a mapping system and (3) is reframing the conversation between hospice and palliative care.
- ToniAnn Marchione spoke about a Connecticut program called Care CHAMPION which is Children's Health Advocacy Management and Palliative Care. She believes that if hospice provides pediatric care, then they should also provide CHAMPION care. This would allow hospice services to be administered before they make the six-month determination. She believes that large hospice agencies should service all ages and that private insurance should be following Medicaid and Medicare rates.
- Regina Owusu asked if the model that they are building could combine palliative and hospice care for pediatrics instead of just having hospice. She also asked if private insurance is paying in a particular case, can payment be switched to Medicaid after private insurance runs out.
- Kerry Moss answered that they can have Medicaid as a secondary at a certain financial point. She agrees with Barbara Cass's three recommendations and believes that they need to look at a mapping system. She believes that they need to reframe the conversation to show a different lens when they are discussing how to provide services to pediatric patients when compared to adult patients.

- Melissa Witthoft believes that setting a vision for what they think is the right solution is a good starting point. She believes that they will have to ask for an aspirational solution and then figure out the “devil in the details” along the way.
- Barbara Cass believes that the first step is going to have to be branding. She likes the model of CHAMPION care and the CHAMP acronym.
- Melissa Witthoft stated that they do not have to go with CHAMPION or CHAMP care as she was coming up with nomenclature to discuss a model.
- Jazmin Johnson asked if they specified what services fall under palliative care to distinguish hospice and palliative care.
- Melissa Witthoft believes that right now decisions may support the need for palliative care and later, they may need hospice. It is a judgement call on the medical provider to help families understand.
- ToniAnn Marchione commented on the difference between adult and pediatric hospice patients as lifesaving interventions are not being serviced to adult patients, but they may be to pediatric patients. She stated that they are not entering a pediatric patient home as typical hospice. She agrees with Jazmin Johnson about distinguishing services between hospice and palliative care and mentioned the model of Washington where palliative falls under hospice care.
- Regina Owusu asked if they can combine palliative and hospice care for pediatrics under the CHAMPION model.
- ToniAnn Marchione responded that is what she hopes they pursue as a solution.
- Jazmin Johnson asked if they would be combining or creating a smooth transition between the two.
- ToniAnn Marchione answered that they would be creating a smooth transition between the two, and worst-case scenario would be combining them. The new model would allow services to be provided if you are licensed for home care.
- Jazmin Johnson commented that this is like hospice and agrees that it would be creating something new as you are merging two similar services that would see patients from one end to the other.
- ToniAnn Marchione asked how they would ensure that pediatric nursing is in the rotation for programs at universities.

- Melissa Witthoft agrees with Kerry Moss's point about the mapping system allocating resources more effectively.
- ToniAnn Marchione commented about the Massachusetts's model and how it is entirely state funded.
- Jazmin Johnson likes the Massachusetts's model, but she would like for it to be sustainable.
- Barbara Cass asked if there are any regulatory barriers about creating a new model of combining palliative and hospice care and if she needs to take back anything to a work group that is revising home care regulations. She asked if it would be helpful to map out every home care and hospice agency in the State.
- ToniAnn Marchione stated that her issue from the Department of Public Health (DPH) is the dealing with oasis on the adult side when she would like to deal with pediatric patients.
- Barbara Cass asked if doing an oasis assessment for a pediatric palliative patient is a barrier.
- ToniAnn Marchione responded that this is not a barrier. She also asked if they are offering that service if they can only offer it to pediatrics.
- Barbara Cass will follow up with an answer.
- Jazmin Johnson answered they may make it across the board and asked about recruiting staff who already work in pediatrics.
- ToniAnn Marchione agrees with Jazmin Johnson and believes that it should be part of the rotation for programs.
- Barbara Cass asked what they would need to create a center of excellence for training.
- ToniAnn Marchione answered that she would need prospective applicants for the center as she already has educators.
- Barbara Cass asked if that would be a pathway for the certification exam.
- ToniAnn Marchione answered that they are not providing classroom time but the rotation and education.
- Jazmin Johnson asked If the center of excellence would be with ToniAnn Marchione.

- ToniAnn Marchione answered affirmatively and added that they would work with universities to develop the program. She asked if there are incentives to retain staff that are already in the State.
- Barbara Cass added that workforce strategy is already working on those mechanisms.
- Jazmin Johnson asked Barbara Cass if workforce strategy had the same goal but there were no incentives. She commented about the incentives of providers going to Federally Qualified Health Clinics (FQHC).
- Barbara Cass added that could be a model to mirror.
- Kerry Moss asked how the training would translate to the workforce and believes that there could be a model where pediatric nurses could do pediatric hospice and their original pediatric role.
- Melissa Witthoft mentioned that could be part of the mapping system.
- Kerry Moss believes that they need to think about young nurses as it would be hard to specialize on just pediatric hospice. The problem currently is that they do not have the trained staff to most effectively use the staff that they have.
- ToniAnn Marchione asked if they discussed the amount of pediatric hospice patients that do not use any type of service and if there is an estimate.
- Regina Owusu commented that she is currently working on that with Jazmin Johnson and that they have a meeting with the Katie Beckett Program to look at the data.
- Kerry Moss asked if the data includes those who are on the wait list.
- Jazmin Johnson answered that they will try to get that data and that they will ask any question that any member believes is pertinent.
- Kerry Moss commented that there are about five hundred kids on the Katie Beckett wait list and asked if that is correct.
- Jazmin Johnson answered that she wouldn't be surprised if that was the amount of people on the wait list.
- ToniAnn Marchione asked what the Katie Beckett Program is.
- Jazmin Johnson summarized what the Katie Beckett Program is.

- Barbara Cass asked if they knew how individuals get connected to the Katie Beckett Program and commented that there could be individuals who are just not connected to services.
- Jazmin Johnson agrees with Barbara Cass about individuals who could just not be connected to services as there are countless services out there.
- Melissa Witthoft asked if they knew how many pediatric patients are receiving services through private insurance.
- Jazmin Johnson suggested that the Office of Health Strategy (OHS) would have a better answer.
- Melissa Witthoft commented that there could be an equal number of pediatric patients who are getting support through private insurance as could be waiting on the list for the Katie Beckett Program.
- Barbara Cass reiterated and agreed with Jazmin Johnson's point regarding the complexity of the support system. She added that data is helpful and that they should highlight any data in the final report. She asked if they ever established how many home care hospice agencies have the capacity to serve pediatric hospice or palliative patients.
- ToniAnn Marchione agreed with Barbara Cass about data being important and that this should be highlighted.
- Barbara Cass added that this will inform decision making.
- ToniAnn Marchione believes it will be critical to know the amount of pediatric hospice patients who could be benefiting from these services.
- Barbara Cass asked if the researcher from Yale has any data that they could use and added that she could send out a survey to licensed home care and licensed hospice agencies.
- ToniAnn Marchione believes that the survey needs to ask when a provider last treated a complex pediatric patient and how many were treated in the last year.
- Barbara Cass stated that she will draft a survey and share with members for input and revision.
- ToniAnn Marchione believes it will be interesting to see how many more children benefited when Washington and California did these pilot programs.
- Barbara Cass asked ToniAnn Marchione if they should ask that in the

survey.

- ToniAnn Marchione responded affirmatively and asked members if they can meet again in January.
- Barbara Cass suggested DPH as a location to meet.
- ToniAnn Marchione stated that Hartford would be the best location to meet.
- Kerry Moss suggested the date of January 29th to meet.
- ToniAnn Marchione asked for the time of the meeting on the 29th.
- Administrative staff noted that the Connecticut General Assembly is in session and the Working Group will need to keep that in mind when scheduling.
- ToniAnn Marchione agreed with DPH as a location to meet.
- The Working Group agreed to meet at DPH on January 29th from 1:00 PM to 2:00 PM.
- Regina Owusu asked about the presentation that was shared.
- ToniAnn Marchione answered that the presentation was compiling everything that came up in the meetings.

IV. Adjournment

- The meeting adjourned at 3:53 PM.