State of Connecticut
GENERAL ASSEMBLY

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

Working Group to Study Pediatric Hospice Services

Meeting Summary

Tuesday, February 25 ,2025

2:00 p.m. On Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by ToniAnn Marchione at 2:05 p.m.

- Attendance: ToniAnn Marchione, Rep. Nicole Klarides-Ditria, Dr. Ross Albert, Barbara Cass, Karen Garlie, Regina Owusu, Tracy Wodatch

- Guests: Melissa Witthoft, Brian Cournoyer

II. Recap of the Sub-Working Group activities

- ToniAnn Marchione stated that she spoke with the co-chairs of the Public Health Committee regarding an extension of the Working Group and language. She believes there is a lot of work to do, and that the legislature will be able to lead them down a reasonable path. She added that they are looking for funding from the State to be able to help run the program and that it is extremely difficult to acquire data regarding pediatric hospice.

- Barbara Cass gave an overview of her survey.

- Tracy Wodatch asked what acute pediatric hospice care is considered under a pediatric complex care.

- Barbara Cass responded that she would get more information regarding that and continued giving an overview of the survey.

- Tracy Wodatch asked if the survey respondents can be identified as they all look anonymous.

- Barbara Cass responded that she could contact the survey respondents and has the ability to determine who the responded if necessary. She continued giving an overview of the survey.

- The group had a discussion regarding the question of how many cases of pediatric palliative care or pediatric hospice care did an agency receive in 2024.

- Barbara Cass stated that some agencies had inadequate contact information, so they weren't able to receive the survey, but she was able to do outreach to those agencies and continued giving an overview of the survey. She commented that there are less than 20 certified pediatric hospice nurses possibly 14 in the State which she believes supports the idea for a center of excellence.

- ToniAnn Marchione appreciated the survey and shared the story of a pediatric hospice case.

- Referring to the story shared by ToniAnn, Melissa Witthoft added that when they reached out with bereavement services the mother wished they had been aware of these services before.

- ToniAnn Marchione continued sharing the story of the pediatric hospice case. She gave an overview of what a program for pediatric hospice/palliative care might look like. She stated that they can send to members other program models like the hub and spoke model from Massachusetts.

- Melissa Witthoft commented that they have a child centric approach.

- ToniAnn Marchione stated that is a model where the State funds the entire program from a central repository that delegates cases to various agencies. She commented that they have to wait for extra data and asked members if they are missing any perspectives.

- Tracy Wodatch commented that approximately ninety percent of their cases are Medicaid funded which makes them not competitive with out of state rates. She added that a struggle of last-minute hospice care is not being able to make a connection with the family or patient. She believes that many of the pediatric complex care cases fall into the serious illness category. She suggested that funding has to be part of the recommendations. The legislature has to look at the rates in all bordering areas to make the rates reasonable and comparable.

- ToniAnn Marchione agrees with Tracy Wodatch about the funding piece.

- Tracy Wodatch added that most hospice providers in Connecticut take Medicare patients which allow them to sometimes pick and choose clients as well as expand services. However, the agencies that take mostly Medicaid patients don't have that same privilege.

- Barbara Cass asked ToniAnn Marchione if they can meet regarding the data issue.

- ToniAnn Marchione responded affirmatively.

- Tracy Wodatch suggested including the Rare Disease Advisory Council.

- Barbara Cass responded that she would try to reach out to them and asked what happens when a child is diagnosed with a life limiting disease and may need other support services. She asked this to gauge how visible these services are to pediatricians and if there is an opportunity to build a tool kit or resource.

- ToniAnn Marchione stated that she is not sure how visible the services are to pediatricians and commented that most of their referrals are from a palliative care team, a family, or from a hospital. She mentioned that New York seems to have a well-functioning program.

- Karen Garlie commented that from her experience there is no mainstream referral service and mostly it requires word of mouth for services to become visible to providers.

- Ross Albert commented that frequently pediatric palliative care providers at hospitals know who to turn to when referring patients. He agrees that most of the time it is word of mouth instead of it being a true resource.

- ToniAnn Marchione added that in her experience it is mainly word of mouth and may be creating a network.

- Melissa Witthoft suggested creating a pilot program as a start.

- Barbara Cass mentioned that they already completed a pilot program and had successful outcomes that could be applied statewide program.

- Melissa Witthoft commented that it would be interesting to see the results of that pilot and to utilize that experience in their pilot.

- ToniAnn Marchione believes that their pilot will be bigger than the pilot that Barbara Cass mentioned and asked about the time frame for the pilot.

- Barbara Cass responded that she could get more accurate information to the group.

- Tracy Wodatch believes that there is not much transference of the pilot experience to this Working Group and that they already have done most of what a pilot would do. She believes that a pilot is just kicking the can down the road and that something needs to be brought forward.

- ToniAnn Marchione agrees with Tracy Wodatch regarding the pilot program and commented that they wouldn't be able to accomplish any of this without funding, so she believes that it is a center piece for the recommendations. She believes that it has to be a state funded program, or it won't go anywhere. She commented that they have to work more on the data and will work more on the data. She mentioned that they will send out the program model to members.

- Tracy Wodatch asked if it would make sense to list the average length of stay for patients for hospice and listing the challenges for grief and bereavement services.

- ToniAnn Marchione agreed with Tracy Wodatch regarding those suggestions.

- Tracy Wodatch asked Barbara Cass regarding the survey if she is able to share the name of the agencies who have responded.

- Barbara Cass responded affirmatively.

- Melissa Witthoft asked about the timeframe for the report.

- ToniAnn Marchione commented that the legislature needs language for a placeholder bill. She added that they will send out the recommendations and other related documents to members.

III. Proposal: A child-centric service model

IV. Other States' best practices to build a CT solution

V. Recommending a pilot program partnership

VI. Adjournment

- The meeting adjourned at 2:57 PM.