

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

Tuesday, February 11, 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, Dr. Kerry Moss, Sen. Saud Anwar, Dr. Ross Albert, Barbara Cass, Karen Garlie, Regina Owusu, Tracy Wodatch
- Guests: Melissa Witthoft, Brian Cournoyer, Wendy Jiang, Eileen O'Shea

II. Synopsis and Themes from January 29th Sub-Working Group meeting/recap

- ToniAnn Marchione introduced Wendy Jiang and Eileen O'Shea to the Working Group. She commented that the time available to the Working Group could be extended but that legislators need to introduce the necessary language in an appropriate bill.
- Sen. Anwar thanked the Working Group for their efforts.
- Wendy Jiang gave an overview of her white paper regarding palliative and hospice care.

- Melissa Witthoft asked Wendy Jiang when she expects for the white paper to be published.
- Wendy Jiang responded that they hope to publish the white paper by the end of the month.
- Kerry Moss asked Wendy Jiang how she got her state rankings.
- Wendy Jiang responded that she got it from the 2024 score card and is happy to share it with the group.
- Kerry Moss asked Wendy Jiang how requiring larger hospice providers to provide services to pediatrics will look like in terms of translating to clinical care.
- Wendy Jiang gave an overview of the score card and what goes into a ranking. She believes that when a provider reaches a certain size then they should be required to provide pediatric services, but she believes that what size will trigger that requirement will be up to policy makers.
- ToniAnn Marchione commented that there is a population group that would not like to get services in the home and would like to be in the hospital setting. She mentioned that they were looking at providing hospice in a hospital setting but not at the level of general in-patient care.
- Wendy Jiang mentioned a study that pointed out when there were new openings for hospice or palliative services in hospitals, then people utilized those services.
- Kerry Moss commented about sibling exclusion that happens in hospital settings as a contrast to providing these services at home. She mentioned that the biggest limitation to providing hospice at home is the limitation of IV medication, the inability to provide pain management, and system management.
- Tracy Wodatch asked about the rankings. Her understanding is that the data is based on hospital palliative programs and not community palliative care programs.
- Wendy Jiang responded that the data included the availability of community palliative care programs.
- Tracy Wodatch asked who is on the list because she believes that they could be hospitals with a community palliative care program and not licensed hospice care providers. She asked about requiring large hospice providers to service pediatric patients and if Wendy Jiang meant the hospital providers or

hospice providers.

- Wendy Jiang answered that she meant the hospital providers. She commented that recommendation wouldn't be prioritized if they do not find data that supports it from other states.
- ToniAnn Marchione believes that large, licensed hospice providers should be required to service pediatric patients.
- Eileen O'Shea commented that she has concerns about rebranding hospice and palliative care as it would require educating the public and wondered if they should continue clarifying the definitions of palliative and hospice. She added that nurses are already being trained in hospice and palliative care that encompasses all age ranges. She gave an overview of what is happening in nursing education regarding hospice and palliative care.
- ToniAnn Marchione commented regarding the rebranding. She mentioned that multiple stakeholders have trouble understanding concurrent care and that they are looking to try to make it about different levels of care. She added that she even struggles with the difference between palliative and hospice care and appreciates others concerns.
- Karen Garlie commented that she agrees that there will be patients who would like to receive hospice at a hospital, but she believes that a majority would like to receive these services at home. She shared a story of a family who appreciated the chance to have these services at home. She added that it is rare for patients to qualify for a general in-patient level of care. She agrees with Kerry Moss about the limitations of providing hospice at home and commented that her organization is working on solutions to these issues.
- ToniAnn Marchione commented that her organization had minor issues with bringing pumps into the home and doesn't know if it is a localized issue.
- Karen Garlie added that they are starting slow and doesn't know what the future will bring.
- Melissa Witthoft commented about the rebranding and that there are two audiences including patients and providers. She added that the rebranding is mostly for patients to avoid the inclusion of hospice early in the process.
- Barbara Cass gave a preliminary overview of the survey results.
- ToniAnn Marchione asked Wendy Jiang if she could help with the data component of the report and if they could further discuss the demographic data that shows who utilizes these services.

- Wendy Jiang responded affirmatively and commented about a study regrading rebranding and the issue of reimbursement. She mentioned that she would be happy to share a draft with the Working Group. She added that they hope to add on and help the efforts of the advocates and legislators that are creating these policies.
- Tracy Wodatch believes that it is important to differentiate in the survey who is a hospice provider versus who is a general at-home provider. She adds that she doesn't like rebranding and that they should figure out how to use the parallel of home care and home health to illustrate the confusion with these definitions.
- ToniAnn Marchione agrees with the issue about rebranding and commented that it is more about the payments and levels of care.
- Tracy Wodatch added that Connecticut Hospice received a grant to expand their pharmacy for home infusion.
- ToniAnn Marchione thanked the Working Group and announced that the next meeting would be on February 25th at 2:00 pm with the entire Working Group.

III. DPH Survey results

IV. Child-centric service model

V. Key elements from CA, MA, WA programs for the CT program

VI. Next steps/draft timing for Working Group report

VII. Adjournment

- The meeting adjourned at 3:06 p.m.