

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 29, 2025

1:00 p.m. at 410 Capitol Ave and on Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by ToniAnn Marchione at 1:05 p.m.
- Attendance: ToniAnn Marchione, Barbara Cass, Karen Garlie, Jazmin Johnson, Regina Owusu, Tracy Wodatch
- Guests: Melissa Witthoft, Brian Cournoyer

II. Work on building the flow map for a new program serving chronically, acutely, and terminally ill children in the state of Connecticut.

- The meeting had technical difficulties for the first fourteen minutes.
- Tracy Wodatch shared how she wrote a report for another working group.
- ToniAnn Marchione went through the discussion document and asked Barbara Cass about the survey,
- Barbara Cass gave an overview of her survey and its status.

- ToniAnn Marchione asked if only hospice agencies would be identified.
- Barbara Cass stated that they could do that if that is what the group wanted.
- Tracy Wodatch asked if Barbara Cass's map survey would capture the service areas of the providers.
- Barbara Cass responded that she would look into that.
- Tracy Wodatch suggested that when Barbara Cass sends out her next communication blast, she requests that everyone who received the message respond to the survey.
- Barbara Cass responded affirmatively.
- ToniAnn Marchione continued the discussion of the document and suggested meeting two times in February. She believes that the recommendations would result in a true program for pediatric hospice. She stated that over the past ten years her facility served eleven pediatric patients. In addition, she mentioned hearing that there is a population of families who would like to have pediatric patients be in hospice in facilities. She asked if the recommendation could address that request and that pediatric patients would not be receiving services in general level inpatient care.
- Barbara Cass and Tracy Wodatch suggested having a recommendation of allowing the Working Group to continue its work past its deadline.
- Jazmin Johnson stated that families could be afraid to bring pediatric hospice patients' home because they don't have adequate support or knowledge concerning how to take care of the patient. She added that families could be more likely to choose the hospice at home option if they had the necessary support.
- ToniAnn Marchione asked what the cost difference would be between adequate hospice care at home compared to hospital care.
- Barbara Cass asked how families would be notified of all the options that are available and if there could be a recommendation of creating a fact sheet or guide for families to acquire knowledge of services.
- Melissa Witthoft added that if there are areas where medical providers are not familiar with hospice services, this would imply that patients also not well informed.
- Tracy Wodatch asked ToniAnn Marchione if she reached out to The Alliance

as they had a pediatric workgroup, and they could have developed tools that could be reused by the Working Group. She asked if they had reached out to Kerri Padgett to explain what happens when a child becomes eligible for hospice and how the process is managed.

- ToniAnn Marchione responded that they had met with Kerri Padgett. She shared a document regarding the questions asked and ToniAnn's response to the questions.
- Jazmin Johnson added that their program is state funded which gives them flexibility and assumes that most children would continue on the program after they become eligible for hospice.
- Melissa Witthoft added that most of the children in the program are covered under MassHealth which makes it easier for them.
- Jazmin Johnson added that the program has expanded over the years.
- Regarding the program that Kerri Padgett is involved with, Tracy Wodach asked what the next steps are since some patients have been receiving services for nine plus years. She added that Kerri Padgett mentioned that additional legislation is being purposed to alter some parts of their program.
- ToniAnn Marchione agrees with Tracy Wodach and likes the recommendation of extending the deadline of the Working Group as there might be a need to have further conversations.
- Barbara Cass stated that she hasn't seen any document providing guidance to families navigating the process but will continue looking because she believes that their needs to be some sort of roadmap for families.
- Melissa Witthoft added that the program will need a media plan so that stakeholders have a similar level of understanding.
- Jazmin Johnson suggested that the excellence center could be part of the roadmap and could help families navigate.
- ToniAnn Marchione believes that the excellence center could be part of a state program like the Massachusetts model. She cautioned that her center would not be able to supply the number of nurses that are needed in the state. She envisioned a state program or a state-run agency that oversees palliative and hospice care.
- Jazmin Johnson suggested training a nurse educator who would then train nurses with the necessary knowledge.

- Tracy Wodatch stated that she reached out nationally to acquire a guide about concurrent care.
- ToniAnn Marchione summarized the conversation about having a state-run program as well training the nurse educator.
- Barbara Cass asked who was funding the Massachusetts program.
- ToniAnn Marchione responded that it was the state and asked how agencies would provide the service without the funding. She added that they would need to come back to what the child would need. She stated that there is a piece about educating physicians.
- Tracy Wodatch suggested having grant funding recommendations.
- ToniAnn Marchione agrees with Tracy Wodatch and asked how they would extend the deadline of the Working Group.
- Tracy Wodatch answered that they would put that recommendation in the report, or they can ask for a temporary extension from the co-chairs of the Public Health Committee.
- Barbara Cass responded that they could reach out to the co-chairs of the Public Health Committee and ask for a temporary extension or make a more formal recommendation in the report to extend the Working Group.
- ToniAnn Marchione commented that there is a place holder bill regarding the Working Group, and she may reach out for a temporary extension regarding the final report.
- Barbara Cass added that the bill is a placeholder bill that allows the process to move forward.
- Tracy Wodatch added that they would still need to submit a report.
- ToniAnn Marchione asked if the extension got approved would the report still be due March first.
- The group discussed the logistics and process of the legislature.
- Brian Cournoyer added that Public Health has a mid-March deadline that allows the recommendations to be put into bill form.
- Melissa Witthoft asked if they are working with a fiscal year in terms of money.

- Barbara Cass stated that the bill would be analyzed for its fiscal impact.
- Melissa Witthoft asked how the report should be written regarding format.
- Barbara Cass answered that the report should be data heavy as legislators like data.
- ToniAnn Marchione asked if they are missing any perspectives.
- Melissa Witthoft added that they can include the definition of life limiting.
- Barbara Cass answered that they should have the number of pediatric palliative care patients being serviced in the State.
- ToniAnn Marchione commented that if a patient is in hospice or palliative care, she believes that it would depend on the level of funding as well.
- Regina Owusu asked if they are still looking at other state's models and if they could start with a pilot program.
- ToniAnn Marchione responded affirmatively with starting with a pilot program and theorized how a program would work considering today's discussion.
- Melissa Witthoft asked how previous pilot programs have been received.
- Barbara Cass commented that they had a pilot program regarding Medical Orders for Life-Sustaining Treatments (MOLST).
- Melissa Witthoft asked if the General Assembly liked the pilot.
- Barbara Cass answered that the program was before her time, but the program did expand past its initial implementation.
- Brian Cournoyer mentioned that a pilot program is usually championed by a legislator.
- Barbara Cass added that out of the eight responses to her survey three responded that they did pediatric hospice.
- Karen Garlie asked if the funding for the care will be covered by the state or if state funds will supplement insurance? She mentioned that Massachusetts requires insurance plans to have a hospice benefit.
- Jazmin Johnson believes that there is a payment and access issue. She added that her experience with pilot programs shows that they are in response to data supporting the extent of the need for such services. She

believes that it is necessary to look at what other states are doing.

- ToniAnn Marchione asked Tracy Wodatch if she has a contact in California.
- Tracy Wodatch responded affirmatively but added that they are currently busy due to fraud and abuse issues.
- ToniAnn Marchione mentioned that Washington State combined palliative and hospice with a State Plan Amendment (SPA).
- Tracy Wodatch cautioned about the deadline and suggested creating a draft of the final report.
- The group stated that they identified some barriers and those include staffing, funding, access, workforce, and training.
- Barbara Cass asked what the recommendation would be around workforce and mentioned that the State has fourteen pediatric palliative certified nurses.
- Regina Owusu suggested that they could discuss the limitations of the report in the report.
- ToniAnn Marchione asked how they could incentivize providers to start training in pediatric hospice.
- Tracy Wodatch added that there is also the barrier of home care experience.
- Barbara Cass asked if that is a regulatory barrier.
- Karen Garlie stated that there were a group of nurses at Yale Childrens that want to follow the patient into the community, and they are looking at how to facilitate that. She explained that she points this out to indicate that there is an interest.
- Barbara Cass asked how they could expand that to other programs especially since they are restricted by funding.
- Karen Garlie shared that these nurses would follow patients out into the community and those nurses would be trained in hospice.
- Tracy Wodatch suggested grant funding for training.
- Barbara Cass reiterated that they are restricted by funding.
- ToniAnn Marchione commented that they weren't tasked with finding the

funds.

- Barbara Cass stated that they should be aware of the funding situation.
- Regina Owusu added that they have to be creative as well and to see what already exists.
- Barbara Cass agreed with Regina Owusu and mentioned Karen Garlie's nurse example.
- The group discussed the nurse example and the preliminary logistics of a pilot program.
- Jazmin Johnson added that nurses working at hospitals have half of what's already needed. They just need the home care experience and training in hospice. She gave an overview of the Hartford HealthCare Reach program that could be used as a guide.
- ToniAnn Marchione believes that providers should provide service in areas of their care. She stated that they would be happy to become a center of excellence.
- Melissa Witthoft asked if there has to be a defined curriculum for such a center.
- ToniAnn Marchione gave an example of an APRN who is being trained.
- Tracy Wodatch asked if the training is related to pediatrics.
- ToniAnn Marchione responded affirmatively.
- Tracy Wodatch based on that response suggests that materials already exist that can be used.
- Barbara Cass asked as a subgroup if there is any requirement to meet and report to the larger Working Group and if the whole Working Group has met.
- ToniAnn Marchione responded that the whole Working Group has not met but she has been in communication with members about the subgroup's activities. She suggested that the whole Working Group can meet in February.
- Barbara Cass suggested having insurance providers added as members to the Working Group as they could potentially be a missing perspective.
- ToniAnn Marchione responded affirmatively.

- Karen Garlie stated that Massachusetts's required insurance plans to have a hospice benefit.
- Brian Cournoyer stated that there are multiple bills before the insurance committee each year about mandating certain coverage.
- Barbara Cass cautioned that the Working Group could be missing some perspectives.
- Brian Cournoyer commented that they would have to report to the larger group as the report comes from the whole Working Group.
- ToniAnn Marchione asked what a placeholder bill is.
- Administrative staff explained that a placeholder bill is a legislative shell for a larger bill to be put in its place later down the line and explained the committee process.
- Brian Cournoyer added that there are certain deadlines and certain processes used to fulfill those deadlines.
- Karen Garlie asked if the deadline is mid-March for the legislative shell.
- Brian Cournoyer responded that it is March 16th for the Public Health Committee.
- Melissa Witthoft asked if the report has to be submitted at the same time.
- Barbara Cass responded that the report is due March first and that there are two placeholder bills. She explained that it is not unusual to have multiple bills about the same concept. She mentioned that the bill at the end of the process looks completely different than what is currently out.
- ToniAnn Marchione announced that the next subgroup meeting will be on February 11th at 2:00 p.m.
- Tracy Wodatch asked if the future meetings will still be hybrid.
- ToniAnn Marchione responded affirmatively and announced that the subgroup will have another meeting on February 25th at 2:00 p.m.
- Barbara Cass asked if the whole Working Group has to vote on the final report.
- Administrative staff responded that the Working Group has the flexibility to present the report how they wish.

III. Adjournment

- The meeting adjourned at 2:38 p.m.