State of Connecticut
GENERAL ASSEMBLY

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

Working Group to Study Pediatric Hospice Services

Meeting Summary

Wednesday, October 9 ,2024

3:30 PM on Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by Kerry Moss at 3:32 PM.
- Attendance: Rep. Cristin McCarthy-Vahey, Sen. Saud Anwar, Rep. Nicole Klarides-Ditria, ToniAnn Marchione, Dr. Kerry Moss, Tracy Wodatch, Dr. Ross Albert, Erica Alexander, Carl Schiessl, Dr. Stephanie Massaro, Barbara Cass, Karen Garlie, Jazmin Johnson

II. Co-Chairs plan for working sessions with ad hoc members.

- ToniAnn Marchione asked a procedural question regarding the logistics of the Working Group.
- Rep. Cristin McCarthy-Vahey responded to the procedural question about logistics.
- ToniAnn Marchione announced that they will put together a subgroup to determine the legislative and regulatory policies that may be causing barriers to pediatric hospice.

- ToniAnn Marchione asked Rep. Cristin McCarthy-Vahey if this course of action works best for legislators.

- Rep. Cristin McCarthy-Vahey answered and explained the goal of the Working Group and what conversation the group can have and where the conversation can lead.

- Sen. Saud Anwar added that he wants the Working Group to guide the legislators through the process and he hopes that future conversations will clarify issues within the space.

- ToniAnn Marchione announced that they were thinking about forming a subgroup of members.

- Rep. Cristin McCarthy-Vahey clarified how the Working Group information and recommendations will be reported to the legislature.

- Kerry Moss expressed hope that the Working Group will come up with a mission statement to keep everyone on the same page. She went over what she believes is the task of the Working Group prescribed by legislation as well as ways to increase services.

- Barbara Cass shared her experiences of working on other working groups.

- ToniAnn Marchione thanked Barbara Cass for sharing her experiences and explained that creating subgroups is the method to follow.

- Kerry Moss agrees with ToniAnn Marchione that creating subgroups is the method to follow.

- ToniAnn Marchione asked members who would like to be on which subgroup and what the subgroups should look like. She believes that there should be three subgroups based around the tasks prescribed in the legislation.

- Carl Schiessl went over the mission statement in the legislation, and he views the three different tasks in the legislation as connected and not separate and distinct. He also reminded members about the timetable.

- ToniAnn Marchione thinks that Carl Schiessl brought up a good point and discussed the logistics of the Working Group and subgroup.

- Kerry Moss agrees with ToniAnn Marchione and asks Tracy Wodatch if she would help navigate what the hospice services are that children are receiving in Connecticut, what are the resources she would utilize and what expands the question to palliative care.

- Tracy Wodatch asked her if she is asking about the data or the collection.

- Kerry Moss clarifies that she is asking for existing data.

- Tracy Wodatch answers that it is anecdotal based on membership to her association. She believes a survey is the way to capture that information.

- Kerry Moss thinks that the Working Group needs to distinguish between who offers hospice vs who is providing hospice as that is different in pediatric care. She believes to best understand what the state is offering requires that the question be asked in different ways.

- Ross Albert agrees with Tracy Wodatch that it will be mainly anecdotal and asked if they have access to claims data, Medicaid data, or any other market assessments.

- Jazmin Johnson thinks that it is possible, and they will be able to look up billing codes to see what data is available.

- Ross Albert states that it doesn’t cover private insurers, but it is more data than what is currently available.

- Tracy Wodatch added that a grey area in claims is identifying hospice billing claims but is not sure if she identifies palliative care billing claims because it is not coded as palliative care.

- Jazmin Johnson stated that she will add that when she looks for the data.

- Tracy Wodatch suggested to Jazmin Johnson that she might be able to get information from Connecticut Community Health Network, and they might capture that children’s data under their intensive care management.

- Jazmin Johnson stated that she will be reaching out to them.

- ToniAnn Marchione stated that she is frustrated over the distinction of services between pediatric palliative care and pediatric hospice care.

- Barbara Cass believes that ToniAnn Marchione brought up a critical point that needs to be defined in the report as the Department of Public Health (DPH) does license or certify hospice services. She states that if members of the Working Group are frustrated over the distinction, then it critical that it should be clarified for the public.

- ToniAnn Marchione agrees with Barbara Cass and believes that whatever new service is created she hopes that it allows patients to be visited as needed and for shift nurses to avoid burnout and stress.

- Kerry Moss thinks that ToniAnn Marchione identified an important barrier in pediatric hospice which is prognostication and concern of false prognostication for hospice benefits purposes, but it needs to be recognized that it can be the only service available. She believes that they need to be careful in letting vernacular dictate how they are going to do this as they won't be serving the correct population.

- Tracy Wodatch believes that the discussion and the confusion within needs to outline within the report and asked if it would make sense to invite guests to the Work Group.

- ToniAnn Marchione, Tracy Wodatch and Kerry Moss discussed the logistics of inviting speakers to the Working Group.

- Kerry Moss announced the timetable of the Working Group which is that the Working Group will meet at 3:30 PM on November 13th, December 11th, January 8th, February 12th, and March 12th.

- Tracy Wodatch asked Kerry Moss about the timetable and recommendations. She emphasized that the Working Group could meet more than what they have already stated.

- ToniAnn Marchione thanked Tracy Wodatch and stated that they aren't meeting more as not all members are going to have to be in on the work of it. She stated that they will be waiting for Kerry Moss and Tracy Wodatch regarding the speakers.

- Tracy Wodatch and Kerry Moss discussed the logistics of inviting speakers to the Working Group.

- Carl Schiessl asked them to ask the speakers about insights for funding and sustainability.

- ToniAnn Marchione and Tracy Wodatch discussed the logistics of inviting speakers to the Working Group.

- Barbara Cass reminded members about creating a mission statement and wants the Working Group to create a statement to help them stay focused as there is not a lot of meetings.

- Kerry Moss stated that she is coming in this with a different perspective and stated that she and Stephanie Massaro will need to figure out how many children are being serviced in their hospital and they will need to get data from hospitals across the state with the same data as she believes the data is important. She asked members how they interpret the task about providing appropriate levels of hospice services for pediatric patients.

- Barbara Cass believes that it will help keep the Working Group focused as it is a complex issue.

- Kerry Moss agrees with Barbara Cass and adds that it is an emotional issue as well. She asked members what they think their role is in this and what they should be doing in their short period of time.

- Barbara Cass believes that part of the problem is access to care for children who need end of life services and brought up an example of a child who wanted to die at home but couldn't.

- Tracy Wodatch believes that the problem is access to services, having a workforce trained to provide those services and funding.

- Kerry Moss emphasized that they need to keep in mind family centered care when talking about pediatric care.

- ToniAnn Marchione added the difficultly of asking a parent about signing a consent form to put their kids on hospice. She believes that the difficulty in acquiring access is mainly because she doesn't know any other hospice that provides pediatric hospice.

- Ross Albert asked if framing the conversation about access would be a good starting point and from his perspective talking about access than funnels the right appropriate questions to create initiative and groups.

- Kerry Moss believes that asking who is providing the care is the first step and that would be a survey. She asked the members how they can get that information back in the most expedient manner that is usable.

- Stephanie Massaro told the Working Group that she knows someone that drafted a list of the folks who provide pediatric hospice and is happy to come back to the group with that information. She echoed the frustration about people who say they provide care vs who is providing care.

- Karen Garlie added if there is a twofold of do you provide hospice and when was the last time you provided hospice.

- ToniAnn Marchione asked if Jazmin Johnson will be working through the billing.

- Jazmin Johnson answered that she is and has already started it.

- ToniAnn Marchione thinks that starting with who actually billed a pediatric case is good as many hospice services don't provide pediatric services.

- Stephanie Massaro stated that they have partnered with 4 agencies successfully.

- Jazmin Johnson asked if they are still getting data from places where they currently do not provide hospice, but they did recently.

- Tracy Wodatch thinks that information is important to understand why the places have stopped providing pediatric hospice.

- Ross Albert believes that Stephanie Massaro and Kerry Moss would have the best understanding of palliative care billing codes.

- Kerry Moss stated that they try to utilize V codes with every patient for billing and tracking purposes.

- Kerry Moss, Stephanie Massaro and Ross Albert discussed billing codes and how they use them.

- ToniAnn Marchione is glad to hear that they were able to partner with 4 agencies and believes that they know most of the answers for why they can't partner but would like to hear unique answers. She stated that Regional Hospice is looking to become a center of excellence for training in pediatric hospice which could be an answer to things.

- Barbara Cass stated that she can explore through DPH if they can send out a survey and talked about a survey she sent out previously.

- Tracy Wodatch asked Stephanie Massaro about a survey that was sent out previously.

- Kerry Moss answered that a survey was sent out two years ago and will try to come back to the group with the results. She emphasized the timetable of the Working Group.

- Carl Schiessl asked the Working Group if they know what the payer mix is for hospice services for pediatric patients.

- ToniAnn Marchione answered that at Regional Hospice 70% of patients are Medicaid.

- Carl Schiessl asked about the balance of the payers.

- ToniAnn Marchione answered that it is commercial vs charity care.

- Stephanie Massaro and Kerry Moss state that it is accurate for Yale and Connecticut's Children.

- Kerry Moss states that many kids are qualified for Husky and a lot of them have dual payers which makes it complicated.

- Ross Albert states that the number is accurate with his organization as well.

- Carl Schiessl asks if the split is roughly a 70 / 15 / 15 payer mix.

- Kerry Moss think it could be more as most children are going to be covered by Husky. She believes that the split could be 70 / 25 / 5.

- ToniAnn Marchione agrees with Kerry Moss about the payer mix.

- Kerry Moss believes there is work to do to figure out what they already know and the next step is to survey agencies to acquire data which can be utilized to make recommendations. She asked members if they see it the same way.

- Tracy Wodatch agrees with Kerry Moss and stated that she already reached out to invite guests.

- Carl Schiessl agrees with Kerry Moss and stated that Massachusetts pays for their program with appropriations.

- Kerry Moss believes that it may be too long to wait for next steps for their meeting in November. She asked the members about having a different timetable.

- Rep. Cristin McCarthy-Vahey thanked members for the discussion and encouraged them to meet at whatever op tempo they desire but reminded them that they will need to coordinate with administrative staff.

- ToniAnn Marchione stated that herself, Kerry Moss, Stephanie Massaro will be meeting on October 16th and that they can add additional members if they need to.

- Tracy Wodatch stated that she will not be available for the October 16th meeting and believes that solidifying questions to ask in the survey is a path forward.

- Ross Albert added that this would allow his team and ToniAnn Marchione's team to parse through their own claim data.

- Barbara Cass asked if they are doing a survey.

- Kerry Moss answered that they will be doing a survey and they will try to figure out what information they have before they send out the survey.

- Barbara Cass stated that she will start exploring the survey option within DPH and will be happy to help set up the survey.

- Kerry Moss appreciates the help and believes she can get the skeleton of what she believes would be important in the survey.

- Barbara Cass stated that she can start right away and she could have the data ready to present next week.

- Kerry Moss thanked the members of the Working Group.

- ToniAnn Marchione thanked the members of the Working Group.

III. Phase I - Determine legislative and regulatory policies that may need amendments.

IV. Adjournment

- Kerry Moss motioned for the meeting to be adjourned and Tracy Wodatch seconded.

- The meeting adjourned at 4:34 PM.