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, November 13,2024

3:30 PM on Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by ToniAnn Marchione at 3:35 PM.
- Attendance: ToniAnn Marchione, Dr. Kerry Moss, Tracy Wodatch, Carl Schiessl, Karen Garlie, Regina Owusu
- Guests: Brian Cournoyer, Jazmin Johnson, Dr. Kerri Padgett
- Every member present introduced themselves.

II. Presentation and Q&A – Kerri Padgett – Director, Pediatric Palliative Care Network MDPH - Division for Children & Youth with Special Health Needs-Massachusetts

- Kerri Padgett introduced herself and gave an overview of the Massachusetts's program.
- ToniAnn Marchione believes that they need to move palliative care from under Home Care to under Hospice. She announced to the Subgroup that she has written a letter that can be sent to the State explaining to them about something similar done in

Washington. She asked Kerri Padgett if the Massachusetts programs work together.

- Kerri Padgett responded that the funding comes from the State and that all the programs are contracted through them. She commented that there are a few gaps within the State, but they are always looking to contract with new providers to fill gaps. She added that all the programs are run independently but the Department of Public Health (DPH) has created a strong network.

- Tracy Wodatch asked Kerri Padgett if the funding came from the Legislature or Medicaid. Also, she asked when Medicaid came into the picture if it was the case when complex care needs are present.

- Kerri Padgett responded that is correct as the funding comes from the Legislature for the program and Medicaid comes into the picture for complex care need cases. She added that her program doesn't have the same issues as they are legislatively funded which doesn't affect their services.

- Tracy Wodatch asked if Hospice agencies are licensed by the DPH of Massachusetts or if they go by the Conditions of Participation (CoPs) for Medicare.

- Kerri Padgett responded that she wouldn't know the answer to that question.

- Karen Garlie added that they do follow the CoPs.

- Tracy Wodatch asked if they follow CoPs with no individual state license.

- Karen Garlie responded that Hospice agencies are licensed.

- Tracy Wodatch believes that it would be helpful to have sample language, so they are not starting from scratch. She added that they have been in talks with Connecticut DPH to update regulations for seven years and that if something must happen, they have a short time period to get it complete. She stated that palliative care was offered on either side, and they don't have a pediatrics program to begin with, so it's mainly adults and the aging population that are mainly covered under Medicare.

- ToniAnn Marchione agrees that the time is now and believes that the Working Group is an effective platform to induce change. She stated that she can share a letter with the Working Group that she has been working on with her team regarding a State Plan Amendment (SPA) ask. She believes that the problem boils down to not having the opportunity to provide these services the way they are set up now.

- Jazmin Johnson asked for the name of the program.

- Kerri Padgett answered that it is titled Pediatric Palliative Care Network and they are housed within the Massachusetts DPH as well as the seven vendor agencies that are housed within their own agencies. She added that she can share the website with the group.

- Jazmin Johnson asked Kerri Padgett about any barriers about implementing that program within Massachusetts.

- Kerri Padgett answered that they are about to do a retrospective study that will collect all that data. When she got into her position the program was already implemented but some of the barriers still hold true. One of those barriers are access to care as there are still gaps within the State. She added that the vendor model contributes to that issue as they are not a benefit under Medicaid. But they must rely on the vendor system which requires them to convince people that this program is worth doing. She stated that pediatric palliative care is not a money maker, so they have a funding stream to help the program get implemented. Another barrier was the workforce piece as access to pediatrics especially specialized pediatrics was nonexistent when the program started. She believes that a strong point of the vendor system is requiring vendors to educate their staff with access to advanced trainings. She added that when staff are educated and trained, they stick around for a long time which helped in creating a specialized workforce but there persists the issue of hiring people. She mentioned that Massachusetts has a conversation that ebbs and flows regarding creating a benefit under MassHealth that would further expand access and she believes it will eventually happen. She stated that the program must balance access to care versus the integrity of the program and being line item funded gives them that flexibility.

- Jazmin Johnson asked Kerri Padgett what the average utilization is for the program regarding how many patients they see in a year.

- Kerri Padgett answered that many of their patients stick around which wasn’t the intention of the program. She believes that the program must work on acuity and making sure that the program has enough space to care for the highest acuity patients. She added if the patients are transferred over to Hospice they are followed by the program where they are typically visited once a month for nursing and social work but there could be more done if the patient has a higher acuity. The program offers nurse case management not skilled nursing. She added that they are there to help guide palliative decision-making conversations and to help facilitate conversations between hospitals and patients.

- Regina Owusu asked Kerri Padgett regarding the nursing care if they must undergo any specialized training.

- Kerri Padgett answered that it is case management and added that all their nurses are LNC trained, all social workers having advanced trainings as well as all their integrative therapists having advanced certification in palliative and end of life care.

- Tracy Wodatch asked Kerri Padgett if all the providers offering these services are also Hospice providers.

- Kerri Padgett answered that they are.

- Tracy Wodatch asked ToniAnn Marchione about the SPA as that would be with Medicaid funding and a federal match versus Massachusetts funding it with a line item as SPAs are usually state funded with federal.

- ToniAnn Marchione asked the Subgroup if there is a process to provide palliative care under Hospice and then bridge that over to Hospice so that they're not losing their traditional home care if they go on to palliative care.

- Tracy Wodatch responded that for the adult population if somebody is receiving any State funded service, they are put on a care plan and that care plan has a max dollar amount per month. So, if they were to receive any extra services, they've always needed to keep funding it and it is funded by Medicaid. The care plan usually needs to stay within the cap including the additional services and the Department of Social Services (DSS) may be able to grant special authorization to go over the cap.

- Jazmin Johnson stated that they have a medical necessity like clause and are always willing to review any cases. But is not sure about the caps.

- Tracy Wodatch stated that based on her experience dealing with waivers then anything state funded will need authorizations in place.

- Jazmin Johnson added that there is a thin line with crossing over a cap as they could risk pushback from the Federal government.

- ToniAnn Marchione asked if it is less expensive for a patient to be provided palliative care and home care rather than home care and Hospice.

- Jazmin Johnson asked if she meant that it would be less to continue home care services and add on palliative than to go to Hospice.

- ToniAnn Marchione responded affirmatively.

- Jazmin Johnson stated that it would be interesting to see the data and that palliative care and Hospice care are different as patients can stay on palliative for years while patients stay on Hospice for six months. She explained the differences in the services as the length for the patient is different and other services treating the terminal illness stop when put on Hospice. She added that all their Hospice providers are covered and that there is not typically a need for prior authorization. She added that palliative care is a grey area as they do not know how long the patient will stay on the service. She mentioned that she has been seeing more and more Hospice providers having patients that are still getting treatment for everything which she believes adds confusion. She is open to this new type of service, but they must explore this area for Medicaid purposes.

- ToniAnn Marchione mentioned that they have had pediatric patients that have been on Hospice for longer than six months and that concurrent care aids in that. She asked how much it costs to have your average child on palliative care with home care compared to having them on Hospice and home care. She believes that is an interesting question as providing palliative care and home care rather than providing Hospice and home care can be a way to save money.

- Kerry Moss believes that the challenge is using data in the State that is not representative of the services people are getting. She believes that Hospice should be for reserved for those who are at their end of life and not those who are treating themselves with concurrent care. She believes that ToniAnn Marchione's question is important and that they should not use the review of our State to ascertain that information but rather Kerri Padgett's data. She states that they can't use the review because patients receiving Hospice care are being billed as palliative care and vice versa by the virtue of the constraints of home care agencies.

- Kerri Padgett added that pediatric patients take more resources than an adult patient and that they don't have regulation on pediatric Hospice either. She stated that there are many agencies who refuse to treat pediatric patients as well as the reimbursement being different for pediatric patients which she believes contributes to the refusals. She believes that on a national level there must be a conversation because if there isn't then Hospice providers will continue to deny pediatric patients. She also believes that their program was created to bridge that gap which was started before concurrent care which threw things around as well. She added that they have hospice utilization data for families in the program and stated that there are many cases who just never sign onto Hospice.

- Brian Cournoyer asked Kerri Padgett how much funding the program is given through the line item.

- Kerri Padgett answered that it is just under ten million.

- Brian Cournoyer asked if that ten million accounted for the net contracting as well as the education for the providers.

- Kerri Padgett responded that it was all part of their budgets.

- Brian Cournoyer asked if that ten million is covering for their around seven hundred patients.

- Kerri Padgett responded that they have seven hundred thirty throughout the year.

- Kerry Moss asked Kerri Padgett of that funding that is utilized how much is reimbursed by health insurance versus the state budget.

- Kerri Padgett responded that it was nothing.

- Kerry Moss commented that she asked that question as their website states that cost will be incurred or provided at no cost to eligible children and families if these services are already covered by your health plan.

- Kerri Padgett responded that if there are billable services that the agency can bill elsewhere then they are required to do that first. But she added that the services they provide aren't provided anywhere else or covered by anybody else, so they have that language to differentiate between Hospice and other services that are already in place.

- Kerry Moss asked Kerri Padgett about the size of the line item and the history of the size of the line item.

- Kerri Padgett answered that they had a few years where they were flat, but the line item has never gone down and instead the line item has grown significantly.

- Brian Cournoyer added that it started in 2006 and that the line item was around eight hundred fifty thousand dollars.

- Kerri Padgett believes that is correct.

- Jazmin Johnson asked if they were ever thinking of using an 1115 waiver in a way that could be reimbursable and if that would be in the study.

- Kerri Padgett responded that this won't be included in this study and added that MassHealth is looking into this. She stated that there were various times throughout the program that someone has proposed coverage or a benefit and currently there is energy behind that. She believes that to hold in the future and the idea is to create it as braided funding so that they can cover what MassHealth covers.

- Tracy Wodatch asked Kerri Padgett what the response from providers are.

- Kerri Padgett responded that they have worked with agencies to get their overhead costs covered. She added that agencies send in proposals that explain that they can take an x number of patients with a certain amount of funds. She stated that while they have about seven hundred patients, they still have a one hundred fifty patient wait list, and a few towns are not covered. She added that they are working with MassHealth to create that braided funding to provide more coverage.

- Kerry Moss asked if the wait list has grown over the years.

- Kerri Padgett responded that the wait list has not grown over the years instead it ebbs and flows. She added that wait lists have been up recently because of COVID and she believes that they are past that hump as the wait lists have been going down. She stated that she is thinking about eligibility, acuity and creating some measures to make sure that the wait lists are prioritized appropriately.

- Tracy Wodatch believes that makes good sense as they ensure transparency within the program.

- ToniAnn Marchione asked Kerri Padgett if the program asks Hospice providers who want to be involved and then the Hospice will get referrals for palliative or if the Hospice provider has a license to do palliative care.

- Kerri Padgett responded that she doesn't believe that they have a license to do palliative care and that they do not need it in recent years. She added that adult palliative programs have come out of the agencies that they have contracted with but are not required to. She stated that agencies are required to cover patients for pediatric Hospice and reiterated the intention of the program to help bridge families and providers.

- ToniAnn Marchione asked if a pediatric patient will still receive home care if the program or Hospice is in the home for palliative care.

- Kerri Padgett answered that if it is already in place through concurrent care then they should still be able to receive their home nursing. She added that they are separate programs, and they have many cases that require levels of nursing support that is greater than what Hospice can provide.

- Kerry Moss stated that the bigger issue that is happening is pediatric patients who need Hospice support but can’t have both that and home care where even with concurrent care they still must choose one or the other. She has an issue with this as she believes that a family shouldn’t have to make this decision.

- Kerri Padgett agrees that it is a near impossible choice.

- ToniAnn Marchione reiterated that she hears from pediatric nurses that when they have a patient on Hospice, they are still receiving their home care if it’s not the same agency that is providing the Hospice.

- Kerry Moss asked ToniAnn Marchione if she is referring to shift nursing services.

- ToniAnn Marchione stated that she is.

- Kerry Moss stated that is the case because they co-vendor because they have a lot of cases that don’t accept co-vendors and they only get both in the home if they co-vendor. She added that one of the greatest limitations for pediatric end of life care is getting a Hospice or palliative agency to come into a home with a shift nursing agency. She stated that some pediatric Hospice providers provide by default shift nursing because certain modalities don’t have shift nursing which is met with more desire for more shift nursing from Hospice providers and she believes that this model is not sustainable for the State. She asked Kerri Padgett how they were able to cover the map with their seven agencies.

- Kerri Padgett answered that it is on a case-by-case rolling basis as they review the coverage map every two years to make sure that it is still working for people. She added that many of the agencies have grown out of a small catchment area and would slowly take on new towns when the need arose. She stated that still happens now as an agency will add a town to their catchment area if they are willing to take on the patient. She reiterated that they review the coverage map as well as stating that the map has been static for quite a while with few changes.

- ToniAnn Marchione asked from the Medicaid perspective is a child on Hospice allowed to have home care in the home including shift nursing and if it is palliative care, do they then lose their shift nursing.

- Tracy Wodatch responded that she can get that answer by checking in with providers that offer shift nursing and ask what their historical experience has been. She believes that the answer to ToniAnn Marchione's question is no as palliative care is not a recognized as a specialty and is not reimbursed as a recognized specialty but is not sure and will get her a definitive answer.

- ToniAnn Marchione doesn't want her agency to provide traditional home care for adults in addition to end of life care but would prefer to limit it for pediatric patients only. She asked if there is a way for agencies to set up a way to limit home care and end of life care for pediatric patients. She added that they are providing less care through palliative than Hospice and would be willing to provide palliative services, but they would need help with funding.

- Jazmin Johnson stated that she is going to look for an answer regarding the question if a child will lose their home care services if they are on palliative care.

- ToniAnn Marchione asked if anybody else had any questions for Kerri Padgett.

- Kerri Padgett added that she believes that Christine McMichael will have more information regarding the Hospice regulation piece.

- Tracy Wodatch added that Christine McMichael will have the anecdotal pieces from the providers perspective too. She stated that she can ask Christine McMichael to attend the next meeting.

- ToniAnn Marchione stated that the next meeting will be the same time around in December.

- Tracy Wodatch asked ToniAnn Marchione about the California program and if she should pursue someone from there to be present.

- ToniAnn Marchione asked Kerry Moss for her opinion and believes that more knowledge and understanding the better.

- Kerry Moss agrees with ToniAnn Marchione and added that the greatest disparity is the funding and knowing this information will help with the ask for funding from the legislature.

- Kerri Padgett stated that their model is so different right now and that is not always helpful or transferable. She asked that if they do invite people from California, she would be happy to attend as well.

- ToniAnn Marchione responded affirmatively.

- ToniAnn Marchione asked administrative staff for the date and time of the next meeting.

- Administrative staff asked ToniAnn Marchione if she is asking for the full Working

Group or the Subgroup.

- ToniAnn Marchione responded that she is looking for the Subgroup.

- Administrative staff responded that they do not have it currently.

- ToniAnn Marchione with Kerry Moss's agreement made the next meeting a Subgroup meeting. She added that she will get a date and time for the Subgroup and asked members that were going to come back with information to do so.

- Tracy Wodatch stated that her constraint is that she doesn't want to reach out to people without a meeting date so it would be helpful to get a date and she commented that December 11th doesn't work for her.

- ToniAnn Marchione asked if December 10th worked.

- Tracy Wodatch responded that it did not and clarified that the morning of the 11th doesn't work and can meet in the afternoon.

- The Subgroup agreed to meet on December 11th at 2:30 PM.

- Kerry Moss thanked Kerri Padgett for presenting.

- ToniAnn Marchione told Kerri Padgett that she is welcome to come to the meeting with the California program.

III. Follow up to item from previous meetings- Jazmin Johnson's email from 11/8.

IV. Review Washington States policy amendment and waivers

V. Review concurrent care article and innovations for expanding care

VI. Adjournment

- The meeting adjourned at 4:41 PM.