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, October 16,2024

4:00 PM on Zoom and YouTube Live

I. Convene Meeting

- The meeting was convened by ToniAnn Marchione at 4:02 PM.
- Attendance: Rep. Cristin McCarthy-Vahey, Sen. Saud Anwar, ToniAnn Marchione, Dr. Kerry Moss, Dr. Ross Albert, Dr. Stephanie Massaro, Barbara Cass, Karen Garlie, Jazmin Johnson
- Guests: Brian Cournoyer, Jennifer Danieli

II. Discuss policy & regulatory barriers to providing hospice.

- ToniAnn Marchione introduced Jennifer Danieli to the group. She emphasized the goal of the Subgroup. She asked members to describe barriers they see and to clarify what they believe are the issues to providing pediatric hospice. She stated that the certification of a terminal illness is a barrier. She believes that shift nurses go away when the patient is transferred to hospice.
- Ross Albert reinforced that shift nurses go away when patients are put on hospice by using a recent example.

- Jennifer Danieli asked Ross Albert if the patient in the example was on Medicaid.

- Ross Albert answered that he believes that the patient was on Medicaid and will come back with a definitive answer.

- Jennifer Danieli stated that they had patients like that, and they admitted them to hospice but were able to stay in place to take care of them.

- ToniAnn Marchione asked members if they know if there are certain criteria where shift nurses or home care in the home go away when a patient is put on hospice.

- Jazmin Johnson said that she can inquire internally within the Department of Social Services (DSS) and ask if in the scenario where a nurse shift is taken away when a patient is put on hospice, if the payer was changed or was it because home care couldn’t provide the hospice services.

- Ross Albert answered that the home care agency didn’t have a hospice agency, so they weren’t able to switch the patient internally.

- Jazmin Johnson said that Medicaid controls the payment for the most part but will come back to the group with information.

- ToniAnn Marchione asked Jennifer Danieli if they had other patient cases.

- Jennifer Danieli answered that she will have to go back and check, but the patient case about the ventilator sticks out as the hospice agency couldn’t provide that service, but the home care agency could. She stated that they have patients on hospice who are actively being treated.

- Ross Albert stated that they had similar cases and that a barrier is concurrent care as home care can have concurrent care with hospitals but there is a barrier when they need additional home care support,

- Barbara Cass added that it may be payer specific and emphasized that a large majority of patients served are Medicaid beneficiaries.

- Jazmin Johnson had an overview of the data that she collected that was promised last meeting. She stated that the claims data would take too long to collect and asked for the timetable of the Working Group.

- ToniAnn Marchione and Jazmin Johnson had a discussion regarding the timetable of the Working Group and how long the claims data will take to acquire.

- ToniAnn Marchione answered that she should acquire the data as the Working Group has enough time. She asked members if there are any additional barriers.

- Jazmin Johnson does not believe there are additional barriers according to her understanding. She stated that patients went on hospice and that was their primary care, and they are still getting medical care. She believes that the current environment could interfere with the payer mix.

- ToniAnn Marchione asked Ross Albert and Stephanie Massaro if they had any additional barriers.

- Stephanie Massaro went over the scenario where a patient would not be accepted into hospice if they had a treatment going on such as being on a ventilator. She believes that if a patient qualifies for skilled nursing, then it is a barrier to hospice services as they typically don't accept them. She went over the new CMS, Medicaid, CHIP Guidance that could clarify pediatric palliative care.

- ToniAnn Marchione and Karen Garlie asked Stephanie Massaro if she can send the information to the group.

- ToniAnn Marchione asked Ross Albert if he sees any additional barriers.

- Ross Albert stated that the biggest issue is when the patient loses home care agency services when they are transferred to hospice services. He stated that the barrier isn't only to pediatric patients, but adult hospice patients deal with this barrier too. He has not run into the prognostication and certification of terminal illness barriers.

- Stephanie Massaro stated that they have not been sued for being wrong about time of end of life. She asked if there is room for policy around requiring agencies to provide basic pediatric care.

- Barbara Cass asked members if they are aware of any other states requiring that policy as the State has had similar conversations with the hospitals and it would be helpful to understand the barriers or perceived barriers from the industry.

- Stephanie Massaro believes that a barrier is having nurses who feel comfortable providing end of life care to adults and then transitioning them to pediatric patients. She stated that because there aren't enough pediatric hospice patients in Connecticut, pediatric hospice nurses will have to take care of adult patients to stay fiscally sound and many won't. She believes that there are areas in the State where large hospice agencies will not be able to cover and so they must partner with smaller agencies that can.

- ToniAnn Marchione stated that when the State licenses a hospice agency the license should be full spectrum and they should be required to service pediatric to geriatric patients. She emphasized Stephanie Massaro's barrier of not having enough nurses and raised the idea of the state incentivizing pediatric hospice nurses. She believes that the root issue is nursing.

- Ross Albert stated that the State does this with labor and delivery floors where they know there are gaps and hospice agencies are required to do all four levels of hospice care. He believes that Connecticut could put the expectation on hospice agencies to service pediatric patients like the four required levels of hospice care.

- ToniAnn Marchione stated that the goal of the Subgroup meeting was to identify the barriers to care as the barriers could be small and through conversations could identify bigger barriers that they may have missed.

- Karen Garlie stated that even though nurses are a barrier there must be a conversation for other modalities.

- ToniAnn Marchione agrees with Karen Garlie that nursing is the hardest thing to find and asks if Yale has a pipeline to train nurses and is happy to partner with anyone to train nurses. She made a point about funding as they do not currently have a full time experienced specialized pediatric nurse.

- Karen Garlie answered that Yale does have a pipeline to train nurses and are able to partner to get it done.

- ToniAnn Marchione stated that they are an APRN driven agency and they have one family certified nurse, and they don't have another nurse to cover if this nurse is out. She believes that the recommendations need to develop a program where nurses are being trained in pediatric hospice.

- Barbara Cass asked ToniAnn Marchione if the Group would indicate that staff recruitment and retention are the number one barrier.

- ToniAnn Marchione stated that she believes that it is the number one barrier.

- Barbara Cass raised the idea of contacting the Office of Workforce Strategy (OWS) for assistance as they have done similar initiatives with other modalities.

- ToniAnn Marchione added that the Group should think how as a state they can incentivize nurses to go into pediatric hospice.

- Jazmin Johnson agrees with ToniAnn Marchione and thought that contacting OWS to assist the nursing shortage in pediatric hospice is a good idea. She stated that anyone can submit additional documentation to the Department of Social Services (DSS) if there is a need as they have staff to review cases.

- ToniAnn Marchione thanked Jazmin Johnson for mentioning that DSS reviews cases.

- Stephanie Massaro asked members if hospice agencies can meet the need of bereavement services that are requested, and if so, when a pediatric patient unexpectedly passes away is there room to improve bereavement services.

- Ross Albert stated that he hears that sudden deaths are not as formalized as a full bereavement program and as a result are more limited.

- Karen Garlie states that is the same case with Yale.

- ToniAnn Marchione states that bereavements programs are offered to patients on service and have offered services to others not on bereavement services. She states that the services are more group oriented than one on one oriented.

- Ross Albert suggested that there is room for more improvement and education related to bereavements programs.

- Stephanie Massaro believes that they need some amount of focus on bereavements programs as they are very limited and there is room to improve. She believes that it is a statewide need, and that people should qualify for bereavements programs if a patient had an unexpected death.

- Karen Garlie asked the question if hospice agencies or behavioral health agencies will be providing bereavements programs.

- Stephanie Massaro answered that it would be a behavioral health provider inside a hospice agency. She stated that the process could play out in different ways.

- Ross Albert added that most hospice agencies provide bereavement support through a social worker, chaplain, bereavement coordinators, psychiatrist, etc.

- Karen Garlie stated that they don’t bill separately for bereavement services.

- Stephanie Massaro stated that they can’t bill for bereavement services as they are not certified mental health providers. She asked if the bill for bereavement services is going against the child’s medical insurance.

- Karen Garlie and ToniAnn Marchione stated that they don’t bill once a patient dies.

- Stephanie Massaro stated that it should be reimbursable if a mental health provider is being offered.

- Karen Garlie stated that is not the case under the hospice benefits. Once the patient dies the billing ends and the bereavements programs provided are reimbursed under what they charged for hospice care.

- Stephanie Massaro stated it is like prepaid.

- Karen Garlie stated that it is part of the per-diem rate.

- Stephanie Massaro clarified that there is some sort of investment and there is no mechanism to secure bereavement.

- Karen Garlie and ToniAnn Marchione agree with Stephanie Massaro.

- Karen Garlie added that even if they did support them with those services they still can't bill for those services.

- ToniAnn Marchione asked a question about pronouncement and if they are looking to send providers to do pronouncements instead of patients coming to a hospital.

- Stephanie Massaro believes that is Kerry Moss's intention as it works well with patients who are connected to palliative subspeciality services but there still must be some sort of referral pattern. She believes she envisioned something like admission to home and some availability for a pediatric patient to be pronounced at home. She stated that patients and their families have some misunderstanding about hospice services and members of the Group need to be mindful of that misunderstanding.

- Karen Garlie wants a more robust focus to ensure that they can get the benefits that are available and believes that doing a pronouncement at home is a service.

- Stephanie Massaro stated that families who have pediatric hospice patients are the most equipped to accept the limitations of having the pronouncement and believes that the goal is to improve the system and services. She believes that the recommendations need to say that they can do better, kids deserve better, and their families deserve better.

- Karen Garlie added that the Affordable Care Act (ACA) mentions pediatric end of life care and will send information regarding that to the Group.

- ToniAnn Marchione stated that she hears that another barrier is that pediatric patients can get home, but families are not prepared. She asked Karen Garlie what services they provided the patient and family in the scenario where they thought they were ready but weren't.

- Karen Garlie answered that they provided a nurse and social worker to go out for the initial visit and spiritual care.

- ToniAnn Marchione stated that they are training volunteers regarding bereavement services specifically for pediatric patients. She believes that the recommendations need to outline what hospice care should look like for that pediatric family. She asked other members if they have anything to add.

- Barbara Cass asked ToniAnn Marchione if it would be helpful if they were able to make a connection with OWS.

- ToniAnn Marchione responded that any possible resource would be great and believes that it would be helpful.

- Barbara Cass stated that she will try to contact OWS or at the very least identify the problem that has been noted in the pediatric hospice sector regarding retention and recruitment.

- ToniAnn Marchione believes that most of the work does not relate to things that need to be amended but put into place as policy. She believes that any licensed hospice agency needs to provide the full array of hospice.

- Barbara Cass thinks that is the biggest challenge as they need providers as well as having them be competent and skilled.

- Jazmin Johnson asked if they looked at literature to see if there are any recommendations of what to do in situations like this or how other states deal with pediatric hospice care.

- ToniAnn Marchione responded that Tracy Wodatch has contacted people from Massachusetts (MA) and California (CA). She states that MA and CA are the places that do it best and that other states have the same issues that Connecticut has.

- Barbara Cass stated that Carl Schiessl shared information about the MA program as it is a publicly supported program.

- ToniAnn Marchione reiterated that it is a publicly supported program and asked Barbara Cass if she means that they are funded by the State of MA.

- Barbara Cass believes that it is funded by the State of MA

- Brian Cournoyer confirmed that it is funded by the State of MA and was established by their Universal Health Care Law in 2006. It was initially funded through that bill and then it's been funded through the general appropriation fund each year since.

- ToniAnn Marchione believes that it is key and that public funds are a big part.

- Ross Albert believes that it is a small piece as it is a symptom management issue not a problem-solving issue. He asked members if the Emergency Medical Technician (EMT) agencies have a stance or position on how to support some of the gaps that they are talking about.

- ToniAnn Marchione stated that she can inquire in her area as well. EMTs made it clear to her that they do not pronounce pediatric hospice patients.

- Stephanie Massaro mentioned the Emergency Medical Service Committee within Connecticut and that they can reach out. She isn't surprised that EMT's aren't pronouncing.

- ToniAnn Marchione thanked members and stated that on some issues she would like to work more as a Work Group.

III. Adjournment

- The meeting adjourned at 5:03 PM.