State Advisory Council on Quality Care at the End of Life

Minutes from the September 19, 2022 Meeting

Meeting time and place: September 19, 2022, 9:00 a.m., via video conference call.

Council members present: Alan Eason; Paul Ballard (Attorney General's designee); Jane Markley; Rabbi Steve Glazer; Tricia Nay (Maryland Department of Health's designee); Peggy Funk; Sara Hufstader; Gail Mansell; Tiffany Callender Erbelding; Christopher Kearney; Christian Miele (Department of Disabilities' designee).

Others present: Jane Moore; Marian Grant; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Jenny Kraska; Nancy Denebeim; Eric Holley; Stacy Howes; Sarah Oliveira; Tashi Taliaferro.

Chairman Alan Eason opened the meeting. The April 28, 2022 minutes were approved pending receipt of any corrections.

Jane Moore, CEO, Missouri Hospice and Palliative Care Association, presented to the Council regarding Missouri's hospice program in prisons, on the recommendation of Peggy Funk, her counterpart in Maryland. Jane Moore asked the Council what they were looking to do with regards to prison hospice programs. Paul Ballard explained that there was an incident involving a prisoner in a hospital who was not allowed to see a chaplain immediately preceding their death, and that this incident prompted a discussion among Council prisoners regarding the state of end-of-life care for prisoners in general. Alan Eason explained that the Council focuses on various issues regarding end-of-life care such as advance directives and MOLST forms, for example. He explained that the Maryland Division of Corrections is a statewide prison system and Maryland's 23 counties all have county jails. So, a prisoner could be sent to either a prison or a jail in Maryland under the State's jurisdiction or a county's jurisdiction. So, the reason the Council invited Jane Moore to speak was to get an idea of how end-of-care works in another state's correctional system. Jane Moore asked if anyone from the Maryland Department of Corrections was in attendance and Paul Ballard responded there was not.

Jane Moore said this is a complicated topic regarding how end-of-life care works in corrections. She started on her journey in this area back in 2012. She explained that an offender created the logo for their hospice training program because they were trying to involve offenders in the program's creation. She said that in Missouri there are 32,000 offenders and there is a private contract under which Corizon Healthcare provides health care in the Missouri Department of Corrections' prison system. She said it is another layer to deal with if you have a private contractor because not only does the Department of Corrections have to be on board with anything you do, but the private vendor also must be on board from the very beginning. Alan Eason noted that Maryland does contract out the health care services provided in the Maryland Department of Corrections' prison system. Marian Grant said that Maryland, like Missouri, contracts with Corizon, so Missouri's experience with Corizon is very pertinent. Jane Moore responded that Corizon does have contracts with many prison systems.

Jane Moore said that in the Missouri correctional system there are 15 onsite infirmaries. She said that the prisons with infirmaries are the ones they focused on having their

hospice program employees train volunteer offenders and staff because if a prison does not have an onsite infirmary, prisoners are sent out of that prison for their health care. So, the hospice care needs to be provided to the prisoners within the health care system that the prison already provides for its inmates.

She said hospice care services had previously been provided during the 1990's at two locations where they had a lot of life offenders. Because of the state laws in Missouri, many prisoners are going to serve long-term sentences and life sentences without parole. Consequently, they now have a lot more elderly and terminally ill offenders. Thus, they now have advanced care units for these offenders who need additional care or assistance. These advance care units somewhat resemble nursing homes but are not operated like a nursing home.

She said prisons are not made to manage people with advance diseases, for example, offenders with very advanced COPD (chronic obstructive pulmonary disease) or with congestive heart failure. Most of these offenders would already be in hospice care were they in the community instead of in prison. Instead, most of these prisoners who do get hospice care while in prison get this care closer to the end of life than they normally would if they were in the community.

In these advance care units, a patient who is not able to take care of themself is assigned to another offender who is able to take care of themselves, and they are housed together. They help that person with all activities of daily living. So, the fellow inmate was acting in the role of a home health aide. End-of-life care is becoming more of an issue as more prisoners serve very long sentences without getting parole. These offender volunteers did not have any formal training from the prison system's health care provider, Corizon. She showed a picture of a "hospice unit" in the Jefferson City, Missouri, facility when they first arrived that was in disarray and fell into disuse, which was disappointing. They were not using these hospice rooms effectively.

There are criteria in the Missouri prison system that governs who is even allowed to take the training program that her hospice association created. They have not been able to get into the prison system since the Covid pandemic started. They had a training session in February, 2020 right before everything shut down in March 2020.

To be eligible to be trained to provide home health aide services to their fellow prisoners, an offender volunteer must be assigned to a general prison population housing unit. Based on her experience in Missouri, people interested in setting up a similar training program in Maryland should anticipate that its prison system will set up criteria to determine what offenders can even apply to be in the program. For example, in Missouri, a volunteer must be residing in the prison's "general housing unit," meaning they are not being locked down. They also only want offenders to participate if they are going to be in prison for a little while, that is, longer than a year.

She said each prison location has someone who oversees the hospice program, and they would look at the applications from the offenders to determine if they felt like that person qualified for the program and were in good enough health to move patients around, etc. The offender also must demonstrate they have the experience inside and outside the prison system to show they have the necessary maturity to deal with terminal illness and death issues.

She said the hospice team that trains the prisoners consists of a social worker, a nurse, a doctor, a chaplain, and a bereavement person. So, this hospice team teaches from the team aspect of expectations and what they should be doing, etc., if they are going to volunteer to work with hospice end-of-life patients. In Missouri, all prisoners are required to have a job, but this volunteer work does not qualify to meet this job requirement. Thus, this is truly a volunteer opportunity for an offender. Some of the volunteers would work a full job and then sit with a hospice patient for 24 hours. They train these offender volunteers strongly regarding the importance of confidentiality and these volunteers are very good about respecting the patients' confidentiality.

To be successful, she said the prison system must buy into the hospice program and take ownership of it. Even though their efforts had the support of Missouri's Secretary of Corrections, certain institutions within the prison systems were not supportive, which created an obstacle to their efforts. Even when the director is supportive, all their staff may not be on board. For example, they were not able to have special hospice areas in most of the infirmaries for family and friends. To create a successful program, it is also helpful to have the support of other groups in the prison who can help you to understand how to work more effectively within the prison system.

She developed an interest in starting the hospice training program after talking with her counterpart in Maine who had developed a strong hospice training program in their prisons. And Louisiana had also developed a strong hospice training program in Angola prison. She said that both these states had many struggles developing and keeping their hospice care programs operating. Many prisons without such programs often have stories like Maryland in which a chaplain was not present as death was imminent. She started talking with the Missouri Department of Corrections director in 2012. The first meeting did not take place until March 1, 2013, after she put a call out to see who would be interested in being part of a program like this. There was no existing program, curriculum, and no hospices were involved. Corizon was involved in the first meeting and was part of the entire process of developing the curriculum, which she felt was hugely important to its success.

The Department of Corrections and Corizon assigned people to sit in and help develop the program. There are a lot of things hospices teach in end-of-life care that will not get past the prison's naysayers and thus will create a struggle to use the normal curriculum. So, it was helpful to have Corizon and people who work with the Department of Corrections that could say "there's no way you're going to get that through in this training program, so we need to take it out or need to go around it." It was hard for hospice staff or for a clinical staff of doctors and nurses to understand why certain content couldn't be included in the curriculum, but the Department of Corrections had their own ideology about what's safe to say and what's not safe to say, and what you can and cannot teach offenders.

It took them from March 2013 until the first day-long training on May 15, 2015 to develop the curriculum with the blessing and sign-off of every silo in the Department of Corrections and everybody who had something to say about it. Her team kept fighting through all these struggles and never gave up. They did their first training with the curriculum they developed based on a hospice team teaching it. They developed the time frame for the

curriculum but it got changed a lot because every time they went into a different facility they would run into so many of the “how” issues, for examples, there might a lockdown on the training day, one of the offenders to be trained got into trouble, the people who were supposed to do the program with you from the Department of Corrections hadn’t shown up yet, or they wouldn’t let you through the door because they didn’t think you had permission to be in the prison. It was rare to have any training session start on time. And they would have to stop at a specific time to go to lunch and sometimes someone would get in trouble at lunch, and it would then take 2 hours waiting to get started again.

She said that quite often the offenders had no healthcare background nor training in hospice or end-of-life care. So, they started off with a little hospice philosophy, that is, talking about the history of hospice so that the offender volunteers would understand what hospice is about. They spent a half-hour on journaling, so they created a journal form that the Department of Correction approved but later revoked their approval. The journal was intended for the offender volunteer to use while sitting with the patient and the Corizon staff was very much on board with this. The offender volunteers are not medical professionals, but they could write down things the patient said and did while they were sitting with them. They could then hand the journal off to the medical staff when the offender volunteer finished their shift. Thus, the offender volunteer was basically the medical staff’s eyes and ears regarding the patient.

In the training they talked through the role of the offender volunteer based on the Missouri Department of Corrections’ criteria and told the students what they would have to do to stay in the program. They trained them on the medical aspects of life-limiting illness, ethical and decisional issues in prison settings, patient-related psychosocial aspects of death and dying, stress management, spiritual care and cultural issues in end-of-life, instructions on moving patients from bed to wheelchair, toileting and the uses of gloves, and good infection control, because a lot of that had never been taught to offenders and these were not health care professionals. Also, they trained the offender volunteers on the active dying process and presented testimonials of current hospice volunteers which were very helpful because they gave the students some idea of what it is really like to deal with end-of-life patients in the prisons where they were. Her training team evaluated every program, and the team would come back together and discuss how the training went, how they used their time, how they could change things around, or the locations of things, or what things that could be absolutely dropped from the training program.

They did a graduation process which really meant a lot to the offender volunteers who took the training. Many of them had never received a certificate or participated in a graduation of any kind. Many of them had pictures taken and sent them to their families. The certificate was put in their file to take with them if they were going to leave the prison system at some point, which certificate showed that they graduated from this little course that had been created. Also, she was able to get some of the locations they worked with to collect the hours that the offenders volunteered and to give them a certificate about how may volunteer hours they had accumulated. They would then be able to take this certificate with them if they were able to get out of prison at some point. This would perhaps help them get jobs in the workforce by showing, for example, that they volunteered for 600 or 700 hours as a hospice volunteer, which said something positive

about their character. They called out everyone's name, shook their hands and congratulated them, and they were all so excited about this that she can't highlight enough how important it is for people to feel they have accomplished something important in life. They had a purpose in life from being a hospice volunteer in prison. They saw a reduction in offender disciplinary issues in prison for these volunteers because they wanted to be able to participate in the prison hospice program and if they got in any trouble they wouldn't be allowed to participate. And these offender volunteers were very committed to this program, and she wished she had staff as committed as some of these offender volunteers were. They trained a lot of offender volunteers at various facilities within the Missouri Department of Corrections prison system.

She shared some of the statements she had received from offender volunteers: "I have learned compassion from helping others at the end of life;" "I love my hospice work. It has given me a purpose in life;" "His feet never stopped moving so we just stand" (in reference to a patient with restless syndrome at the end of life who the offender volunteer responded to by getting up and dancing with the patient). Many of the offender volunteers found a family with the hospice team because many of them had no contact with family from the outside because they had been disowned. These offender volunteers are very dedicated to their patients. Another comment from an offender volunteer: "We talk to each other about how to handle our bereavement."

Marian Grant said Jane Moore's presentation was very pertinent because Maryland also contracts with Corizon. Marian Grant noted that Maryland does not have advanced care units or a volunteer program in their prison system. She asked Jane Moore if her hospice providers association provided any volunteers to provide care. Jane Moore responded that it was just offender volunteers and Corizon staff. She said some of the Corizon staff had end-of-life training and some had not had any such training. In some cases, the Corizon staff sat in on the training sessions just like the offenders did because they needed the training in end-of-life care. The staff also asked for certificates that they used for continuing education credits.

Marian Grant said certain Maryland prison health care staff she had talked to a couple of years ago also reported to her that they had inadequate training in end-of-life care. So, perhaps a training program for staff could be set up before trying to create an offender volunteer program. Jane Moore said it was a lot of time and effort to set up the offender volunteer training program but was well worth the time and effort. For example, they had to change their curriculum because there were certain things you weren't allowed to say. But they didn't teach down to the offenders and they got the same education that the health care staff received, which training was successful because the offenders were able to understand the contents of the training.

Chris Kearney asked about the extent of Corizon's buy-in. Jane Moore said there was buy-in from Corizon because they did not have the staff to provide this level of care. For Corizon, having the offender volunteers there was like a nurse having an aide available to help with assisting the patient with activities of daily living. So, Corizon staff looked forward to the offender volunteers coming in to help with the patients. It also helped the staff by training offender volunteers on how to properly assist patients with activities of daily living. The staff that worked with the patients in the infirmaries were very good to work with.

Jane Moore said they talked about advance directives in their training program's curriculum for the offender volunteers and one of the things they learned is that the offenders did not realize they could prepare an advance directive. So, many of them had not prepared advance directives and were able to learn about that option. So, that is another topic for the education of prisoners.

Marian Grant asked what the status was of the training program since the pandemic started. Jane Moore said they had not gone into the prisons since the pandemic. They taught all the way up to the beginning of the Covid pandemic. She believed that the training program was well worth doing even though it took a lot of time and effort to develop and implement.

Peggy Funk asked if Jane Moore could share her presentation's slide deck and she said she could share the presentation.

Alan Eason said that having prisoner volunteers provide hospice care to other inmates raised a lot of issues, including patient confidentiality.

Christopher Kearney asked about the present Maryland prison's system of infirmaries. Marian Grant said the Corizon contract does not mention units other than for alcohol, drugs, and mental health issues. There do not appear to be hospice units in any of the prisons. When she spoke to the medical director at Jessup and his staff, they have infirmaries and some of the inmates live in the infirmaries because they are too debilitated to be in their cells, that is, they are bed-bound but they are not in any way hospice units. To create a hospice unit, Marian Grant said you'd have to have a bunch of other things in place that we don't have in place yet.

Marian Grant said that hospice care, palliative care, and chronic care are all included in the Department of Corrections' contract with Corizon. The leadership will be changing at the Department with the election of a new Governor, and it would be an opportunity to ask the Department and Corizon what they are doing regarding end-of-life care. This issue could also be looked at by the palliative care workgroup convened by the Maryland Health Care Commission at the direction of the legislature. If the new administration is interested in this issue, the Council and interested persons could engage in a multi-year process to first ascertain what is going on, what are the biggest opportunities, and whether offenders could be trained as volunteers further in the future. But first, people should ascertain what could be done to train prison health care staff in end-of life care. She suggested that a subgroup of the Council could study the issue and report back to the Council.

Christopher Kearney said Corizon may have evidence from their experience with the offender volunteer programs in Missouri and Maine that these hospice programs were good for their bottom line. He said he spoke with gubernatorial candidate Wes Moore who expressed an interest in the issue. Christopher Kearney said he would be happy to be part of the Council's subgroup to study the issue.

Alan Eason asked if people were interested in participating in a subgroup. Marian Grant volunteered to head the subgroup. Christopher Kearney and Peggy Funk also volunteered to be on the subgroup. Paul Ballard will send an invitation to the Council members and to all interested persons to participate on the subgroup.

Christopher Kearney talked about the palliative care workgroup that the Maryland Health Care Commission convened in accordance with House Bill 378 that had passed in the 2022 legislative session. The workgroup was asked by the legislature to study palliative care health care services in Maryland and make recommendations to improve those services. The workgroup has been asked to study the capacity of Maryland's palliative care providers to do their work and to identify the geographic gaps in these services. The workgroup is also to identify opportunities to collaborate with key stakeholders who are or may be able to develop a strategy and a plan for improving or expanding palliative care services and to study the feasibility of the financial support for long-term expansion, including an insurance plan. The workgroup is also to develop a plan for ongoing data collection for monitoring and improving general palliative care services in the State of Maryland. And finally, the workgroup is supposed to develop a strategy for educating the public. As suggested by Peggy Funk, much of this is modeled on a similar effort in Hawaii.

Christopher Kearney said the workgroup has been convened but he did not yet know who would be on the workgroup, but he did know that Marian Grant and Peggy Funk were on the workgroup. The first meeting was to be held on the Wednesday following the Council meeting. They have a preliminary workplan that the Health Care Commission had sent out which will provide a timeline consisting of eight meetings. A preliminary report will be completed in July, 2023, and a final report completed in November, 2023.

The Commission is reviewing available resources regarding palliative care services such as a previous Commission study on palliative care, an NHPCO (National Hospice and Palliative Care Organization) national study on palliative care includes what the other states have accomplished, and a CAP-C (Center to Advance Palliative Care) report on every State. According to the CAP-C report, Maryland appears relatively well-positioned in terms of the availability of palliative care services. He noted that Maryland law requires that any hospital with over 50 beds must have palliative care services available. Peggy Funk stated that this requirement started in 2015 and was the last bill passed on palliative care.

Peggy Funk said what is really exciting about this new legislation creating the workgroup is that for once they will be able to gather all of the stakeholders around the table, which is very different than what has been done in the past because the insurers, hospital associations, and the palliative care providers along with consumers will all be there, which is very important to get the consumers' perspectives as well. She said that Colorado had just published a great report as well as did Massachusetts, and she thinks the Commission will be looking at some of the California reports. She said the Commission has gathered a lot of background information and that the workgroup will have some really good discussions on this issue. Christopher Kearney said there are a lot of states that have gone beyond Maryland in the provision of palliative care services, including Colorado, Nebraska, South Carolina, California, and Maine. He said there is work to do in Maryland. Even though Maryland appears to have an acceptable level of palliative care services, no one has looked at that issue in awhile to see what the current level of palliative care services is, so that will be interesting to see.

Dan Morhaim asked Christopher Kearney to describe specifically how he believes the other states are ahead of Maryland. Christopher Kearney responded that California mandated

Medicaid to have a palliative care benefit which is the same as a hospice-based benefit but unlike the hospice benefit, the patient is not limited to a prognosis of having six months or less to live and to have given up all other options for care to receive the benefit. He said that it appears other states are ahead of Maryland in providing these types of benefits in their Medicaid programs.

Marian Grant said while we have this Council which is an end-of-life council, other states have focused on palliative care and serious illness specifically. She said those states have councils, coalitions, and workgroups that are much more organized and focused on palliative care. She said we have wonderful palliative care in Maryland's major health systems but not in the community or at home. So, these are issues that other states and cities are exploring. She said Maryland is not doing terribly but that HB 378 creates an amazing opportunity for Maryland to catch up to the efforts being made by other states.

Marian Grant said that the goal of these efforts is to get people palliative care before they are eligible for hospice benefits so that they have a good experience in the last years of their serious illness and maybe get hospice care sooner and for longer. The advantage of doing this a little later than other states is that Maryland now has examples of what other states have done to review. For example, some things worked in California while others did not. Hawaii has benefitted from that learning as have other states and Maryland will benefit as well.

Christopher Kearney said he and Peggy Funk were on a conference call with people from 10 other states and that Maryland was right about in the middle in terms of what it has accomplished. Peggy Funk said that the call was with C-TAC (The Coalition to Transform Advanced Care) and involved State Medicaid directors about expanding Medicaid to cover palliative care. After having all these kinds of conversations, she said that we have learned an awful lot about how to do this and how to move forward. Each state has its own rules and challenges but there is a template that can help Maryland come up with a much better program. Christopher Kearney will report back to the Council on the workgroup's activities.

Paul Ballard said he had been talking with Nikki Majewski about coming to a Council meeting to address the Council's concerns about the implementation of Senator Kramer's bill regarding the integration of electronic advance care planning documents into CRISP, the State-designated health information exchange. The next meeting will be scheduled to accommodate her schedule.

Jeff Zucker said the federal government and other states have been watching what Maryland has been doing and the text of Senator Kramer's bill is finding its way into legislation being introduced in other states. So, he said that Maryland should be proud of being a trend setter.

Alan Eason said his term as Chair would be ending and he will serve until someone else is appointed by the Governor. If anyone is interested in serving as the Chair, they can notify Paul Ballard who will tell them what they can do to apply.

Steve Glazer thanked Jane Markley and other members of the Council whose terms are expiring. He invited them to continue to attend meetings because their input is very valuable. Alan Eason agreed. Paul Ballard thanked Alan Eason and the Council members for their work.

Gail Mansell thanked people for what they presented at the meeting, and said she felt it invigorated the whole process of palliative care and end-of-life care. Tricia Nay also thanked the Council members for all their work on the Council.

Christopher Kearney recognized the example that Queen Elisabeth gave us regarding how to live long and die well. He admired that she stayed home and died peacefully in the company of her family. She provided a global example of what we would all hope for and aspire to.

There being no further business, Alan Eason adjourned the meeting.