State Advisory Council on Quality Care at the End of Life

Minutes from the February 28, 2022 Meeting

Meeting time and place: February 28, 2022, 10:00 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); Susan Lyons; Gail Mansell; Peggy Funk; Stevanne Ellis (Department of Aging's designee); Tiffany Callender Erbelding; Christopher Kearney; Sara Hufstader; Shahid Aziz; Karen Smith; Donald D'Aquila: Christian Miele (Department of Disabilities' designee); Senator Ben Kramer; Elena Sallitto.

Others present: Marian Grant; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Stacy Howes; Jenny Kraska; Harold Bob; Pat Alt; Sarah Oliveira; Michelle Ross; Rachel Nathan; Julie Deppe; Neil Rosen; Hank Willner.

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

Senator Kramer discussed his legislative efforts regarding improving access to electronic advance directives, that is, his introduction of Senate Bill 824. He said he had been working diligently with Delegate Bonnie Cullison who had introduced House Bill 1073 to try to put together a solid bill that would help make the public aware of advance directives and get their advance directives into a system accessible for physicians, particularly for emergency room physicians. He thinks the bill he introduced this year is more expansive than the bill he introduced last year in that regard and he said that Dan Morhaim and Jeff Zucker could talk about an amendment they put in at the very end with Delegate Cullison to try to make sure the insurance entities are doing their part of the process and doing it well to communicate the message about advance directives. He said because Delegate Cullison chairs the subcommittee of the House Health and Government Operations Committee that has jurisdiction over the bill, hopefully she will be able to facilitate House Bill 1073 coming out of that committee.

Dan Morhaim thanked Senator Kramer and Delegate Cullison for their work taking the lead on the bill. He thought the hearing before the House Health and Government Operations Committee went reasonably well. He said Jeff Zucker gave great testimony as did Dr. Elizabeth Clayborne, and as did Ted Meyerson of AARP. Dan Morhaim submitted written testimony. David Sharp of the Maryland Health Care Commission testified in favor of the bill. Dan Morhaim said he didn't know to which subcommittee the bill would be sent but thought that Delegate Cullison would be influential. Matt Celentano testified for the insurance industry and they favored the amendments that Senator Kramer and Delegate Cullison had outlined. He also noted that there were some other amendments from the Attorney General's Office that were suggested just for clarification and were not controversial. It is typical for the Health and House Government Operations Committee to hand matters over to their subcommittees, which they did in this case. He believes the Committee will come out with a pretty good bill but that one can never know what is going to happen in the legislative process. He encouraged everyone at the meeting to contact their legislators in support of House Bill 1073 and Senate Bill 824.

Senator Kramer agreed with Dan Morhaim that it is very important to contact all the members of the House Health and Government Operations Committee where the bill has been heard so they are familiar with it. It is nice to get support in advance of a bill but he thinks it gets lost on a lot of the Committee members because they don't know what the bill is and they haven't heard it in committee yet. He encouraged people to contact each and every member of the Committee regarding how important it is to pass the bill. Dan Morhaim said it was important to communicate to legislators via whatever media they wish to use, whether by mail, phone calls, or email regarding their support for the bill. In response to Alan Eason's and Senator Kramer's request, Paul Ballard said he will send the House Committee members' email links to everyone on the Council for them to send their emails of support for the bill. Alan Eason hoped that the bills will fill some important gaps and holes in the use of, and access to, advance directives, and expressed his hope that the bills will pass.

Marian Grant gave a presentation regarding the lack of adequate hospice care in Maryland prisons. Marian Grant is a palliative care nurse practitioner at the University of Maryland medical center. She is also the senior regulatory advisor for C-TAC, the Coalition to Transform Advance Care, and a health care policy consultant for CAPC, the Center to Advance Palliative Care.

Marian Grant said there is no hospice in Maryland prisons. She described her experience with a patient who was an inmate from Jessup in her role as a palliative care nurse at the University of Maryland hospital. He was 79 years old, had kidney failure, was on dialysis, was bedbound, was very confused, and had several recent hospital admissions because of trouble with his dialysis access. When she did a physical exam of his feet, she realized he was shackled to the bed which is the protocol for these inmate hospital patients. There was a guard in the room with him who was on his cell phone because the patient wasn't going anywhere or doing anything. The inmate had requested compassionate release which had been denied. She made recommendations for his care and he went back to Jessup. He died during a subsequent admission to her hospital without a palliative care services team being present. Thus, she has no idea what the quality of care was for his last moments alive.

Subsequently, Marian Grant contacted the medical director at Jessup. He said the patient had been well known to the health care staff and had been living in Jessup's infirmary for a couple of years before he died. The medical director said the health care staff would love more help with end-of-life care. She then spoke at one of their staff meetings where the staff shared their ambivalence about sending dying inmates to the hospital because they didn't want to send them away and yet they didn't feel confident about their end-of-life care skills. So, her conclusion at the end of that experience was there was suffering for all involved. Because she had opened a line of communication with the medical director, she tried to pursue things and this presentation is what she had learned over the last year.

Marian Grant said the health of people in prison nationally is not good. There is a higher prevalence of people in prison with chronic health issues, substance use and mental health issues. A lot of people end up in prison because they have behavioral issues and there are not wonderful resources in the community for mental health or substance abuse. She learned that Medicare,

Medicaid and VA benefits do not cover health care for incarcerated beneficiaries. Thus, the inmate is entirely at the mercy of whatever health care the prison health system provides. Evidence shows that correctional health care is of lower quality, difficult to access, expensive, and that most prison systems charge prisoners a copay. This was unbelievable to her that prisoners get charged for their health care they need in prison given the little money that they make. She said it is estimated that for every year in prison, life expectancy is reduced by 2 years. She noted the prisoner she saw was 79 years old and had been in prison for 40 years but perhaps could have lived to 100 years old. There is certainly clear evidence that the age of the prison population is increasing and this is driving up health care costs just like the aging population is driving up health care costs for the general society. Data from the Pew Charitable Trusts from 2016 showed a sharp increase in the age of prisoners 55 and older because of the increase in prison populations prompted by the harsh criminal sentencing requirements imposed in the 1990's and early 2000's, which resulted in long prison terms for relatively minor crimes.

Marian Grant said that Maryland is one of 20 states that do not provide health care services directly to prisoners but instead contracts out these services to vendors. Maryland contracts with Corizon Health, the largest for-profit health care system for correctional institutions in the nation. The statewide prison system has 27 institutions ranging from super maximum security to community-based facilities. All have infirmaries, some have inpatient medical care facilities, all of which are licensed by the Maryland Department of Health and certified by the Maryland Commission on Correctional Standards. Data from 2018 show there are about 36,000 prisoners in Maryland, 18,000 of which are in State prisons, 11,000 of which are in local jails, and 5,800 of which are in federal prisons. Thus, there are a broad range of facilities and what health services are available in one facility is not necessarily available in another facility. In Maryland, even though African Americans make up only 29% of the population, in the prison system they make up 68% of the prison population. People from minority communities have historically not had good access to health care and have had disparate care because of racial injustice and so they are sicker in prison than they probably would be otherwise.

Marian Grant looked at compassionate release in Maryland. FAMM, a national nonprofit organization, had conducted a 2018 state-by-state analysis of compassionate release policies. Maryland provides compassionate release to Maryland prisoners through 2 options. The first option is medical parole for those with serious medical conditions. So, theoretically, someone who has a terminal illness could qualify for medical parole. The second option is geriatric parole for certain individuals who are age 60 and older who could obtain parole for medical or age reasons and are then sent home or to inpatient hospice or wherever they need to go. The patient she saw last year could have qualified under both these options but his request for parole had been denied. When she saw him, given his condition it was hard to imagine what safety issues there would have been had compassionate release been granted. Jeff Zucker asked if anyone even knew whether these opportunities for him to be released existed. Marian Grant said an appeal had been filed to the parole board but it had been denied, so he and his family were aware of this option. But she is sure a lot of people don't know about these options. When she talked with representatives of FAMM and they learned she was from Maryland, they were excited to talk to her because they felt she could help fix the gaps in Maryland's statutes, regulations, and

agency policy, for which there is little information regarding terminology, assessment, and decisions processes. Maryland does not have a good system and people with a legal background might wish to explore these problems because there is not much that medical people can do about them. FAMM was close to uploading an assessment for 2021.

Neil Rosen said the Maryland Alliance for Justice Reform has a behind-the-walls working group. He said there is a bill to revise medical and geriatric parole that is currently pending. He said he would send to Paul Ballard a link to the Maryland Alliance for Justice Reform and links to their information regarding these bills and their study on the issue that they published in 2019. Marian Grant said that is wonderful news. She said that the Council may want to consider monitoring this issue and maybe even support these bills because clearly the care for these people is not good and if they could get out into the community they would have a chance at accessing hospice or palliative care.

Dan Morhaim complimented Marian Grant's slide deck and said he had already sent it to several State legislators who he knows are interested in criminal justice and health issues. He said the companies that often provide health care in prisons have glorious looking websites but it doesn't work out that way in reality, and is just part of the prison industrial complex, for example, $5.00 for a phone call and paying for their health care. In California, things got so bad there was a huge lawsuit and they had to raise salaries to attract clinicians to work. And it is not just salary but also the feeling you can't be an effective clinician in the prison setting.

Marian Grant said Maryland previously had hospice care in prisons. She pointed to a Journal for Palliative Medicine article from 2002 or 2003 that talked about how Joseph Richey hospice, a Maryland hospice care program, provided hospice care services to prisoners in the Jessup and Hagerstown facilities, mostly for male inmates. That was funded by a Ryan White grant because at that time a lot of prisoners were dying from AIDS and they wanted to get them better care. The hospice did provide the range of services provided by hospice care programs, including medical care, social work, pastoral care, mental health services, and community volunteer services. But it was tricky to provide these services because it is a dangerous environment. The challenge is to balance sending clinicians, volunteers, and other resources into a dangerous environment to provide appropriate care along with obtaining the security you need in the prison. According to the article's authors, inmates are reluctant to die in prison. The fact that they had to accept a DNR order to get hospice care services, which was a requirement in this particular case, was problematic. She also read about this same problem in other articles she read. Which begs the question that wouldn't be lovely to talk about providing palliative care earlier in their illness so that people wouldn't have to be talking about their code status. But neither hospice care nor palliative care is available in the prisons. The article concluded that this was never a high priority in Maryland and the moment the grant funding ended so did the program. The clinicians at the State prison system she talked with did confirm they have palliative and chronic care. These care services look nice on paper but she is not sure how robust their implementation is. Her sense from colleagues that have worked in the prison system is that this is not typically where the best graduates from nursing or medical schools go to work and that they get very poor or no training.

Marian Grant also said she contacted the Humane Prison Hospice Project that was founded by a former prisoner. Their mission is to implement end of life care in prisons by supporting and training prisoners to be the caregivers. They believe that dying with dignity and care is a human right and that people don't forfeit that right by being in prison. Prisoners are trained as volunteer caregivers and this model has been used by over 70 prisons in the nation over the last few years. They believe it is humane not to be moved, that prison is often home and that other prisoners are like family. This program reduces cost by keeping prisoners in the prison rather than transporting them back and forth to the hospital. Prisoners receiving hospice care have extremely low recidivism rates. It is transformative for the prisoners, the staff of the prison, the families, and the community, and thus is a win-win situation.

Marian Grant said that any solutions to this problem would require agreement from both the State and the prison health care system. While there are some things that could be legislated, at the end of day the Council would need to work within the existing structure. The medical director at the prison system she talked with last summer had since left and she didn't know who the new medical director is. She repeatedly tried to contact people in the Maryland Department of Health but they did not respond to her emails. So, she didn't know where things stood.

Marian Grant said that Maryland could try to provide palliative care and/or hospice care in the prisons and could do that through the efforts of Hospice and Palliative Care Network of Maryland members. She said she has talked with Peggy Funk of the Network and there is interest in doing this. But Marian Grant is not sure this would be a financially attractive service for hospice care programs to provide because payment might be limited since Medicare is not going to pay for these care services. Instead, they would be paid by Corizon and she's not sure how much they would pay them. When Joseph Richey hospice did this 20 years ago, the State had a policy against prisoners being volunteers because they didn't want a prisoner to be in a position of undue authority over another prisoner. So, they couldn't use the volunteer model of providing hospice care. So, if the Council wanted to recommend that model, the Council would have to see if that policy would still be a barrier. If prisoners could be volunteer caregivers, we could provide end-of-life care training for prison staff and many people would be willing to do that. For example, she offered wellness training for the nursing staff. But the prison system would have to agree to receive such training. She hopes Neil Rosen and the Maryland Alliance for Justice Reform will help to address the regulatory discrepancies that get in the way of providing hospice care and palliative services to prisoners. Also, staff at her hospital dealing with a more recent case of a prisoner had no previous training in providing care for prisoners at the end of life.

Alan Eason thanked Marian Grant for her focus on all of the different factors. When he started as an Assistant Attorney General, all the health care for prisoners was provided by State employees and as Marian Grant noted, it is now a contractor who provides these services, which adds even another layer to the various issues. Peggy Funk thanked Marian Grant for her presentation and said the same presentation she made to the Hospice and Palliative Care Network in Fall of 2021 got a lot of their members thinking about this particular issue. As Peggy Funk has started talking to people, she has really heard the same types of stories and the barriers noted by Marian Grant in her presentation. Peggy Funk said the biggest barrier is that the health of prisoners is contracted out to a company that is very hard to deal with. And then there is the issue

of having prisoners being able to be volunteers in the system to be trained to provide these services. She does think the Council could make some inroads in the General Assembly on this issue. She said she had a counterpart in Missouri's hospice association who could present to the Council about their wonderful training program and how they do it. The Council could then get some ideas about how to move forward and advance this initiative in Maryland. She would be willing to ask her Missouri colleague to present to the Council. Alan Eason liked this idea.

Gail Mansell asked whether the medical staff at the hospital expressed any interest in receiving training on providing palliative care and hospice services to prisoners. Marian Grant said they were very interested in receiving training. She said they had contacted the hospital's palliative care clinical team because they had no idea what else to do. The challenge of training medical staff in the hospital is that they have so many other things they need to learn besides providing this service to prisoners. Thus, it would be unrealistic to make such training mandatory for nurses in the hospital. Gail Mansell said Marian Grant's presentation was compelling and that the presentation itself might motivate people to want to make changes.

Christopher Kearney said these patients will likely die in prison and that is where they are going to need hospice care services. Volunteers are a fundamental part of hospice care which is difficult to provide in the community and even more difficult to provide in a prison. Regarding payment, if the contractor providing health care services is not part of this effort, he did not know how it would ever go anywhere. It would seem to him that the State of Maryland would have leverage over the company through requiring that hospice care be part of the contract. That's easier said than done but without that it is hard to imagine that there will ever be proper ongoing hospice care in prisons. Marian Grant responded that the prisoner is not going to die in prison but is instead going to die in the hospital because the prison staff do not feel confident about their end-of-life care skills. Thus, prisoners are going to be transported back and forth from the prison to the hospital and many of them are going to die with strangers in the hospital, all at great cost to the State and without providing great care to them. Christopher Kearney said that the hospital is the last place any of us wants to die but if the services are not paid for in the prisons, it is hard to imagine them getting the same care they would get in the community. Marian Grant agreed.

Alan Eason said it would be important to know whether the contract with Corizon covers palliative and hospice care, and if not, how much more it would cost for the prison health care contract to include these services. He thanked Marian Grant for bringing this issue to people's attention and hoped they will be moved to take actions to address the issue.

Christopher Kearney said there are real cost implications to the State of Maryland for sending prisoners to the hospital and providing them with care that is very expensive, not very effective, and not even wanted. If the State was willing to twist the arm of the contractor to give real hospice care, these generally pointless trips to the hospital could be avoided. Marian Grant asked whether the Council would be willing to pursue this issue with the Maryland Department of Health to have a further conversation about this. The Department sent policies to her and she wondered whether those policies are the same policies they believe to be in effect with Corizon.

She questioned whether people in prison actually are getting palliative care and hospice care given that the health care staff in the prison told her they are not providing such care.

Peggy Funk said she is hearing that prisoners are often getting compassionate release and asked whether a prisoner becomes eligible for Medicare or Veterans' benefits kick once they get compassionate parole. Marian Grant said very few people are getting compassionate release. Jeff Zucker said this is a very important issue and thanked Marian for focusing on it. He said that Corizon is a company that is about 10 years old and is a merger of two companies. In the middle of the pandemic it was taken over by a private equity firm. Private equity firms manage to the bottom line because they are trying to dress up the numbers and then flip it. It would seem to him that an outreach from the State to Corizon's leadership to say this is an issue and before it hits the headlines and gathers momentum we would like to work with you to bring in services to alleviate this problem. Corizon would like to keep its contracts and get more contracts to raise the value of the company and to ultimately sell the company. They'll get more contracts if Maryland is the showcase for the quality of care across the whole spectrum. So, it would seem like the nonconfrontational approach would be to propose how the company could provide these health care services more humanely and at a lower cost, which would be in everyone's best interests. The medical director at the local level really didn't have the money or authority to do anything. The CEO of Corizon has no health care experience whatsoever. They are just managing to the bottom line and probably don't even realize that this is an issue that could become problematic. Jeff Zucker believe it would be very worthwhile for the Council to lead such a consensus-driven effort for the State to come to a productive agreement with Corizon to address this issue.

Tricia Nay suggested that Marian Grant let Paul Ballard and her know who she talked with at the prison to make sure she interacted with the best possible people to get information. Tricia Nay suspected that the contract with Corizon is a public document and the Council could look and see what the contract requires or doesn't require Corizon to do. If the contract already requires them to do something, then it is a matter of holding them accountable for what's in the contract. Paul Ballard said he thought the contract would be public information. Marian Grant said she would share the information as suggested by Tricia Nay.

Shahid Aziz asked in Chat what conditions would make a person over 60 years old get paroled early. Marian Grant said she is not familiar with the chapter and verse of the regulations. She would imagine that someone who is having age-related debility or decline might be able to ger released from prison if they are no longer a threat to society. It could be dementia, it could be physical frailty, who knows.

Peggy Funk discussed House Bill 378. She said that a few years ago there were several individuals, including Marian Grant and Christopher Kearney, that were part of an initiative to bring a serious illness coalition to Maryland. The Hospice and Palliative Care Network of Maryland really tried to make this happen. The workgroup had a lot of good conversations, there were a lot of good meetings, and lots of people around the table. But in the end they just weren't able to bring it to fruition due to the fact there was no way to fund it to make it sustainable. So, as they continued talks within the Network's palliative care committee, they happened to come

across a study that Hawaii did. They simply had asked that their Department of Health study palliative care in Hawaii.

Peggy Funk said the Network's committee looked at what Hawaii had done and concluded this is what Maryland needs to do, that is, to do a thorough study to determine what it is needed in Maryland. And then they thought about who can do this and who can make this happen and be able to properly fund it. What came to mind was the Maryland Health Care Commission because they convene these workgroups all the time, they've done some pretty good work, and they're able to build consensus and then make recommendations back to the General Assembly. And so that is basically what House Bill 378 does, which bill is sponsored by Delegate Kerr. What the bill does is ask the Maryland Health Care Commission to convene all of the stakeholders, including hospice and palliative care providers, the health care facilities, patient advocacy groups, and health insurers. The bill asks the workgroup to study the state of palliative care services Maryland currently has, the capacity of those services in the State, and any areas where there are significant gaps, opportunities to collaborate with key stakeholders, and to study the feasibility of financial support for the expansion of palliative care services over the long term, including the provision of insurance coverage.

Peggy Funk said they are hoping this will lead to a benefit in Maryland which is so desperately needed. Also, they want to see the collection of data and measurable outcomes. They also want to see engagement strategies for educating the public about palliative care that empowers individuals to really make the best decisions for themselves and their families. There was a legislative hearing on the Wednesday before the Council meeting at which hearing Peggy Funk testified along with Dr. Eric Bush from Hospice of the Chesapeake and Mike Brady, also from the Hospice of the Chesapeake. The Maryland Health Care Commission has supported the bill. They also have support from the Alzheimer's Association and Leading Age. She asked if anyone wishes to support this legislation to please let her know. And she could help with any letters of support that people wish to submit.

Christopher Kearney said this bill falls under the great category of unfinished business. He and Marian Grant and Peggy Funk and other people in this group had been involved with this issue for a long time. They were jealous of progress being made in other states. He is in favor of HB 378 individually and would like the Council to support the bill as a group. It was the consensus of the Council to support House Bill 378.

Alan Eason introduced the next item on the Council's agenda about the discussion of studies regarding advance directives and the criticism of them. He noted that the Council had a long discussion about this issue at the last Council meeting. Christopher Kearney said he was the one who raised the issue at the previous Council meeting in January. Since that meeting, Jack Schwartz sent a reminder to the Council about the handbook he wrote for proxy decision makers that is available on the Attorney General's website. Christopher Kearney admitted he hadn't seen the proxy handbook and thought it was a very comprehensive and useful tool. If he wasn't aware of the handbook, he was certain that others were not aware of it either. Paul Ballard noted that the American Bar Association also endorsed the handbook and that it is a quality document.

Alan Eason then brought up as a matter of interest a brief article about Idaho having a law requiring women who are pregnant to have life-sustaining treatments implemented against their wishes. Paul Ballard clarified this would not be the case under Maryland law.

Dan Morhaim and Christopher Kearney thought the JAMA article was misleading and not supported by the evidence the authors cited. Jeff Zucker thought it was best to ignore the article. Shahid Aziz said that at the end of life 100 percent of the time the question that comes up is what life does that patient want, that is, what quality of life does the patient feel is meaningful. He said everyone on the Council believes in the importance of advance care planning and should continue with that work. Paul Ballard commented on the importance of educating family members on how to think about these issues and recommended people use the proxy handbook developed by the Attorney General's Office.

Gail Mansell asked on Chat how many prisoners died each year in end-of life care. Marian Grant didn't know if that is reported data. Elena Sallitto said she was struck by Marian Grant's presentation which was amazing. Elena Sallitto was concerned this is a population that is easily ignored. She wondered if there was any way to get statistics on how many prisoners die without palliative care. If there is any data that would support any study, legislation, or policy changes, that would be helpful.

Jeff Zucker said that people on the call should write letters in support of HB 1073. He recommended that the Council should write a letter supporting HB 1073. The Council agreed to send a letter of support.

The Council also agreed to send a letter of support for House Bill 378.

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