State Advisory Council on Quality Care at the End of Life

Minutes from the November 9, 2023 Meeting

Meeting time and place: November 9, 2023, 10:00 a.m., via video conference and in-person at the Office of Health Care Quality, 7120 Samuel Morse Drive, 2nd Floor, Potomac Room, Columbia, Maryland 21046-3422.

Council members present: Christopher Kearney; Paul Ballard (Attorney General's designee) (in-person); Jane Markley; Peggy Funk; Gail Mansell; Donald D'Aquila; Shahid Aziz; Delegate Ashanti Martinez; Tricia Nay (Maryland Department of Health's designee); Sara Hufstader.

Others present: Steve Levenson; Jack Schwartz; Ted Meyerson; Dan Morhaim; Jeff Zucker; Kathrine Ware; Stacy Howes; Jenny Kraska; Tammy Turner; Eleanor Tanno; Linda DeFeo; Anita Tarzian (via AI assistant taking notes).

Chairman Christopher Kearney opened the meeting. The September 22, 2023 minutes were approved.

Christopher Kearney welcomed Delegate Ashanti Martinez as a new member of the Council appointed by House Speaker Adrienne Jones. Delegate Martinez started his political career at age 14 as a Prince George's County Young Democrat. He interned for the late Congressman Elijah Cummings and Steny Hoyer among others. He is interested in improving health care and working for criminal justice reform. Delegate Martinez said he was honored to be appointed by Speaker Jones to serve on the Council and he looked forward to helping the Council continue its amazing work.

Christopher Kearney discussed National Healthcare Decisions Day and the Maryland Department of Health's Cancer Collaborative's Advance Care Planning Workgroup, which workgroup is doing quite a bit of work in the area of advance care planning. He said it may be a good idea for the Council to consider joining forces with the workgroup to work on National Healthcare Decisions Day. Paul Ballard said he was pleased to learn about the workgroup but wasn't sure whether the Council could join the workgroup or whether the Council could just assist the workgroup with any activities they have that may promote advance care planning such as National Healthcare Decisions Day. He asked Dan Morhaim for his thoughts.

Dan Morhaim said he has been going to the workgroup's meetings and said it is not a big group and that only 5 or 6 people have been in attendance. But it is the same discussion about increasing advance care planning that is taking place of the Council and he believed the Council should coordinate with the workgroup. He suggested that the Council leadership either invite to the next meeting, or call Brian Mattingly, the Director of the Cancer Collaborative, to find out more about what the workgroup is doing and for them to learn more about what the Council is doing, especially regarding National Healthcare Decisions Day.

Christopher Kearney noted that from reading the workgroup's minutes, he learned that there is funding from the Maryland Department of Health for outreach efforts to increase advance care planning. Peggy Funk said she used to work with this workgroup but has not been as active recently. She said that the Hospice and Palliative Care Network of Maryland has

collaborated with the workgroup on a number of events providing continuing education. Most recently, they held a nice patient navigation network in Howard County which was really very well attended and was very helpful for patients. She would recommend that Brian Mattingly be invited to the next meeting and give a little overview of the workgroup because recently they changed the direction of what they are doing and they have a grant from the National Institute of Health, which is how they are funded. She said she has served on the Cancer Collaborative for a long time and that they do some really good work.

Dan Morhaim agreed with the idea to invite Brian but again suggested that Christopher Kearney and Paul Ballard call Brian Mattingly to discuss what they are doing before the next meeting. Peggy Funk noted that the Cancer Collaborative cannot be involved in any legislation. Jane Markley was thrilled to learn that there is another group working in this arena besides the Council. Peggy Funk noted that other groups are doing these kinds of presentations, but they work in silos, so we don't always hear about what they are doing. She would report to the workgroup on what the Council was doing in this area. She thought that working with the Cancer Collaborative would strengthen the Council's initiative in this area. Dan Morhaim noted that the distinction is that the Maryland Department of Health's Cancer Collaborative and the Council are both agencies in State government which allows a lot of room for more collaboration between them, which is different from working with private groups that are working in this area. Christopher Kearney said that he and Paul Ballard would call Brian Mattingly to discuss the work of the Council and the Advance Care Planning Workgroup in this area and to invite him to a Council meeting.

Christopher Kearney discussed the Palliative Care Services Workgroup formed by the Maryland Health Care Commission in accordance with legislation. The workgroup's recommendations were presented to the Maryland Health Care Commission on October 19, 2023. The workgroup's extensive report on the state of palliative care in Maryland and its recommendations were unanimously approved to be forwarded on to the Governor, which has been done, and the report has been released for public awareness. Paul Ballard said the legislation required the Maryland Health Care Commission to send the report to the legislature and if a legislator wanted to, they could introduce a bill to carry forward those recommendations requiring legislation. Otherwise, there is nothing that automatically happens after the report is sent to the legislature. At this point, the Commission has completed the task assigned to it by the legislation.

Christopher Kearney discussed what the report's recommendation included. He said there were 6 recommendations including: (1) public education about palliative care, (2) provider education, (3) financing (which he believes is the biggest issue), (4) the development of community-based palliative care (which he said is really the target of the study that resulted in the report), (5) ensuring quality or quality improvement, and (6) continuing to survey or continuing to monitor palliative care in the State of Maryland. He didn't know whether there was anything more for the Council to do with regard to the recommendations.

Peggy Funk said the bill that created the Palliative Care Services Workgroup was put forward by the Hospice and Palliative Care Network of Maryland and they were really fortunate to get the bill sponsored by Delegate Ken Kerr. She said the report will go back to the General

Assembly and Delegate Kerr will review it. She will also be reviewing the report with her board of directors and the legislative committee within the network. Then, they would like to see some legislation introduced but at this point the Council cannot do too much more unless the General Assembly is able to help with funding some of the educational campaigns. That is something that could be possible. But as far as palliative care benefits are concerned, she really feels that the National Academy for State Health Policy's (NASHP) two-year project that Maryland is involved in will provide good information upon which legislation could be based. She doesn't know how we can legislate palliative care benefits until we know who is going to be covered by the benefit and what the cost of the benefit would be, which information the NASHP project will provide.

Christopher Kearney agreed and said the Council approves of all the report's recommendations. He would be supportive of the Council promoting the implementation of these recommendations. Gail Mansell agreed that the Council is available to help as needed. Peggy Funk suggested that the Council send a letter of support for the workgroup's recommendations to the General Assembly to show that the Council was on the workgroup and that it supports the recommendations. This would be helpful to keep the legislators aware of this issue. Christopher Kearney agreed that the Council could say it supports the recommendations and stands ready to be helpful in any way. The Council agreed to submit a letter. Peggy Funk will draft the letter and Christopher Kearney and Paul Ballard will edit it.

Christopher Kearney discussed the NASHP grant that Maryland is working under to figure out how a community-based palliative care benefit could be funded primarily through Medicaid. Maryland was one of 6 States chosen to participate in the NASHP grant as part of a workgroup of experts in financing palliative care from national palliative care organizations, this is a very useful opportunity to enable the Council to think about how we can promote palliative care as a Medicaid benefit for instance. Hawaii is their guiding light as a good example to follow.

Peggy Funk said the NASHP grant is a two-year project. She said they are almost a year into the project. The goal is to develop some kind of palliative care benefit for the State of Maryland. Others in the group of 6 States include Ohio, Colorado, Maine, Texas, and Washington. Not everyone is approaching this issue in the same way. So, even in Maryland, there are three ways that they are examining regarding how to create a palliative care benefit. First, they could take the same approach Hawaii took of getting a palliative care benefit through a State Medicaid Plan amendment, and she agreed with Christopher Kearney that Hawaii is their guiding light. Second, they could do it as a Medicaid benefit. Third, given Maryland's total cost of care plan, they could use the Medicaid waiver as an innovational project.

The goal of this project is for NASHP, who is providing actuarial and a lot of other expertise to Maryland that it would never be able to afford otherwise, to help Maryland examine these options. They are looking at issues like who should be included on the interdisciplinary team that serves patients in Maryland, what a palliative care benefit will look like, and identify what populations will be receiving the palliative care benefit. There is a lot of data analytics that are involved and so Maryland's representatives are extremely happy to be part of this group of

States in the project. She will update the Council on further developments and believes the next 6 months should be very interesting.

Christopher Kearney said the Council members and interested persons are very involved with the Mayland delegation under the NASHP project, including Peggy Funk and Marian Grant. Ben Steffen from the Maryland Health Care Commission and Trish Roddy from the Maryland Medicaid Program are the other members of the Maryland delegation. Christopher Kearney thought the results of the project's work could be a game changer for seriously ill patients in Maryland to be able to gain access to palliative care. He found it interesting that Hawaii was approaching the issue from the standpoint of palliative care being preventive health. He believed this was wise because palliative care practitioners have always known that if you get there early, you can change the course of serious illness, both symptom-wise and how the condition is handled and how people are cared for, which can also mean a patient doesn't have to be in an emergency room on a regular basis.

Gail Mansell said that Christopher Kearney and Peggy Funk did a phenomenal job in capsuling and explaining the Council's efforts relating to the promotion of palliative care. She thinks these projects are just extraordinary. Given the Council's efforts in this area, she recommended that the Council consider adding the word "palliative" to its name. Christopher Kearney also complimented Marian Grant for her critical work on these projects. She was the person that wrote the proposal that was irresistible for NASHP when considering whether to include Maryland in this grant.

Christopher Kearney next discussed the issue of care given to seriously ill patients who are incarcerated in the State of Maryland, which care is not optimal. The Council got more interested in this issue in 2022 when the Council realized that the contract with private contractor who provides that care in Maryland was up for renewal and that perhaps there was an opportunity for the Maryland Department of Public Safety and Corrections to improve this contract in the area of palliative care for its seriously ill incarcerated Marylanders. The Council has talked with the Department's Secretary and her medical director, Oscar Jerkins, who shares the Council's concerns about the quality of care given to seriously ill incarcerated individuals. The Request for Proposals (RFP) was sent out recently and Dr. Jerkins has been responsive to the Council's inquiries. Christopher Kearney asked Kathrine Ware to talk about some of her efforts in this area.

Kathrine Ware said that at the last Council meeting she expressed her idea regarding the possibility of shining some light on this issue as a veterans' issue in light one of the Governor's stated policy priorities to help veterans. So, she reached out to Tony Woods who is Maryland's Secretary of Veterans Affairs to ask what percentage of incarcerated Marylanders are veterans. He then reached out to Secretary Scruggs of the Department of Public Safety and Corrections who provided him with some raw numbers. As of September, 2023, Secretary Scruggs said there were 666 incarcerated veterans, one third of whom are over the age of 60. National statistics from the Bureau of Justice say that about 8% of the total incarcerated population in the United States are veterans. She noted that Professor McKew at the University of Baltimore Law School whose students have been working on advocacy related to incarcerated veteran more in the global sense of pods within the correctional system where they group veterans together to

address issues specific to veterans and to provide services to them in a more efficient manner. Thus, it is a smaller number of veterans than the Council had anticipated. Of course, the goal of the Council is to improve the quality of care for all incarcerated Marylanders. Christopher Kearney did not have more information to add.

Christopher Kearney said that Dr. Jerkins had thanked the Council for their involvement with discussions about what she be included in the new contract. Dr. Jerkins said that he would include requirements in the RFP that would assess functional status and symptom management, particularly pain and debility in incarcerated Marylanders, and that would involve palliative care as part of the audit measures for his team. Christopher Kearney believed this is a positive development and that Dr. Jerkins knows the Council is available to help.

Dan Morhaim posted an article in Chat regarding Maryland prison care: https://www.thebaltimorebanner.com/community/criminal-justice/yescare- Dan Morhaim said that taking a job as a prison physician, nurse, or physician assistant, is daunting work and it takes a special person or a lot of money to get people to do it. The article talks about some of these companies with for-profit private equity investors that impact the quality of care. There are a lot of reasons why it is harder to get good quality care behind bars. Christopher Kearney said that Maryland's contract is worth around a billion dollars. So, there is a lot of interest in providing this care.

Christopher Kearney discussed the issue of possibly changing the Council's name, which he said has been brought up a number of times in Council meetings. The background on this issue is that the Council has been in existence since 2002. The Council was created to have a permanent body considering issues relating to care at the end of life. There has been concern in recent years that the term "end-of-life care" seems somewhat limited and in some ways confusing to people that all the Council cares about are people that are dying. So, across the nation, the term "seriously ill" has become a more favored term because care such as palliative care is not just provided at the end of life.

Christopher Kearney said that Marian Grant raised the issue with the Council's workgroup regarding whether the Council's mission also needed to be revised. The workgroup believed that the Council's existing mission as stated in the statute was sufficiently broad to encompass all the activities the Council is now doing and the foreseeable activities that the Council would be doing, and that changing the name of the Council might be the simplest solution to make it more clear to the public what the Council is actually doing. The name "The Maryland State Advisory Council for Quality Care for the Seriously Ill" would be a common version that we see across the United States and would reflect more accurately what the Council does. It certainly includes care of dying patients, but it broadens that to chronic illness and people who are suffering with multiple illnesses for long periods of time but not actively dying.

Jack Schwartz, who played a major role in getting the original legislation enacted that created the Council, said that at the time everyone was still in the world of the classic living will, and so, palliative care wasn't really a part of policy makers' awareness then. So, they used the name that reflected the primary focus of the Health Care Decisions Act. He agreed that it is time for a change to the name of the Council. He suggested a slightly shorter name such as "Advisory Council on Serious Illness Care." He also thought the Council has a hook based on the

recommendations of the Palliative Care Service Workgroup because they talked about education, and they talked about monitoring. And while the Council can't be a day-to-day monitoring group, it can play a role in the monitoring of the provision of palliative care in Maryland. So, the Council has a decent argument for why a name change is timely given those recommendations in the report.

Peggy Funk added that a secondary benefit of such legislation would be to raise awareness of the Council's existence. This legislation would bring the Council to the attention of the legislature and other key stakeholders. She agreed it would be good to modernize the Council's name. Gail Mansell agreed, saying that rebranding never hurt anybody that needed a marketing push. She said that the beautiful thing about such legislation is that because the Council has no budget and has no funds, it is not like the Council has to invest a lot of money in changing everything as the result of a name change.

Shahid Aziz asked whether the Council's mission statement must be changed along with the change of name given that the Council is already doing what the new name would indicate. Christopher Kearney agreed that the Council's existing mission statement would already be consistent with the new name. He thought that trying to change the Council's mission statement may bog down the legislation. As he said previously, he thinks the mission statement is sufficiently broad to encompass the new name. Paul Ballard agreed that the Council has a very broad mission statement and that Jack Schwartz and the other bill drafters had anticipated the need for its breadth. Paul Ballard said he liked the name for the Council that Jack Schwartz suggested.

Gail Mansell asked Paul Ballard whether the legislature would have to act in order to change the Council's name. Paul Ballard responded that it would take legislation to establish a new name for the Council. Gail Mansell asked Delegate Martinez whether he would be willing to introduce a bill to change the Council's name. Delegate Martinez agreed to introduce a bill. Dan Morhaim said that a bill to change a name is very straight forward and that when he was a Delegate, he had introduced a bill to change the name of the "Department of Health and Mental Hygiene" to the current "Maryland Department of Health." He suggested Delegate Martinez could cross-file the bill with Senator Ben Kramer. He also agreed with Christopher Kearney that the format of the Council's charge is currently sufficient and that simply a name change would be far less controversial and easier to pass than trying to change something of a substantive nature. Christopher Kearney said that Jack's suggestion of "Advisory Council on Serious Illness Care" was very appealing to him. After further discussion, the Council unanimously approved supporting a bill that would change the Council's name to "Advisory Council on Serious Illness Care."

Christopher Kearney discussed suggestions that were made in the workgroup about adding more categories of members to the Council. It was the consensus of the Council not to seek such changes at this time and to keep the legislation to simply being about the name change.

There being no further business, Christopher Kearney adjourned the meeting.