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Hospice and Palliative Care Advisory Board Meeting

May 8, 2025, 10:30 a.m. – 12:30 p.m.

525 W. Jefferson, 4th Floor, Springfield

122 S. Michigan Ave, 7th Floor, Room 711, Chicago

Meeting link: <https://illinois.webex.com/illinois/j.php?MTID=mfd40a1b714fea5d0733151c27ca49572>

Meeting number: 2862 952 0804

Password: 4a2JDAkJb2P

Join by video system dial 28629520804@illinois.webex.com

You can also dial 173.243.2.68 and enter your meeting number.

Members Present: Kristin James, Ellen Byrne, Hakeem Bello, Susan Fristad, Molly Chapman, Shelly Taylor, Becky Dragoo

Members Absent: Shawna O'Dell, Paul Hutchison, Doug Irvin, Jeffrey Workman

Department Staff: Karen Senger, Siji Varghese, Jackie Richmond, Rebecca Gold, Sean Dailey, Sara Ettinger, Stephanie Glenn

Guests: None

Introduction of Committee Members and Guests

Karen Senger, Division Chief of Division of Health Care Facilities & Programs called the meeting to order at 10:32 a.m. and announced that this is the Hospice and Palliative Care Advisory Committee Meeting with today's date being May 8, 2025.

Karen Senger reminded Members and Guests that this meeting is being conducted via Webex and gave a brief explanation of the protocols for conducting this meeting. This is a public meeting, and it is subject to the Open Meetings Act (OMA) and a recording of this meeting is permitted. Today's meeting is being conducted via Webex, which allows audio and other information said during the session to be recorded. By joining this session, you are automatically consenting to such recordings and if you do not consent to be recorded, then you should not join this session. This introduction statement is being read so everyone is aware that this meeting is being recorded.

Since we are conducting this meeting from the Springfield conference room via Webex, you will need to please mute your phone or computer when you are not speaking so we do not get the echo feedback from members and guests of the public that wish to speak. Members of the Public and others wishing to speak will be recognized by the chair during public comment period, which we will open the floor at the end of the meeting for open discussion/comments.

An introduction of Board members was conducted to establish a quorum. After a roll call was conducted, a quorum was established at this time and the meeting was called to order.

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Approval of Draft Minutes for November 14, Meeting {Vote} {Exhibit 1}

The draft meeting minutes from November 14, 2024, were reviewed and discussed by the Board. Karen Senger asked if there any questions or amendments to the meeting minutes. Not hearing any concerns, a motion was made to approve the minutes by Board member Hakeem Bello and 2nd by Ellen Byrne. With none opposed, the minutes were affirmed and unanimously carried to approve the minutes as presented.

OLD BUSINESS

Subcommittee Serious Illness update {Exhibit 2a Draft of Palliative Care Legislation 4.29.25, Exhibit 2b IL Palliative Care Subcommittee – Adult Palliative Care Standards}

At the end of the last meeting, we presented the Palliative Care Subcommittee's recommendations for standards for adult palliative care in the state of Illinois. How do we codify those standards in statute or in administrative rules? Karen had recommended that we should commit those to a statute and her suggestion was to look at a law that passed a few years back regarding dementia care services. It established that you can't call yourself as a provider that specializes in providing dementia care unless you meet certain standards that the state has put forth. We've drafted a bill that we will put before legislature at some point to create a similar set of standards and legal requirements. We will continue to meet and revise. Please review and send suggestions.

The purpose of this Act is to establish minimum standards for community-based value to care for adults diagnosed with serious illnesses. We've outlined definitions. We want to specify that anything that is outside the hospital would be considered a community-based value of care. The Alzheimer's Disease and other Dementias Act, it's explicitly stated that in that case, the act does not apply to physician's license to practice medicine in all it's branches. So that's difficult because we want this to apply to physicians who are practicing. We may need to talk to the Illinois State Medical Society about this and see if they have any suggestions on how to thread that needle, making this law applicable across community settings, including a physician outpatient practice. Karen agrees that the Medical Society is a good place to start. I would question the section mentioning End Stage Renal Dialysis, as we no longer license them, so we will want to remove that. Those are only Medicare certified providers at the time. We've also defined the appropriate population, directly coming from the work of the Palliative Peers subcommittee.

Palliative care patients would not have enrolled in hospice yet. They would have unmanaged symptoms, with no current diagnosis of six months or less. They don't want to give up on treatment and don't want to leave with a gap in care. They would have a diagnosis of qualifying health conditions with evidence of functional limitations. It must be more serious than home health can assist with. They may or may not meet home bound criteria. An expected prognosis would be twelve months to two years but doesn't need to be certified as terminally ill. We've all agreed that we aren't going to be creating another entity to be licensed. How would we know if they are complying if we are not surveying them? There will be an attestation form.

There was much talk of specific standards including diagnosis, which is not appropriate to put in the statute. That's for the Administrative Rules to specify more on.

If anything conflicts with the Licensing Act, the Licensing Act will take precedent. We don't have a current public model in Illinois paying for palliative care, but other states have a benefit available for dual eligible patients in their Medicaid population, so this could be down the road.

24 months after adoption of the rules, the department would convene a work group to assess how we're doing running this program.

We wanted to potentially require some type of a requirement for a public awareness campaign, but we know that the state is in a difficult budget period, so we are holding that aside for now. We will be talking to some additional stakeholders including the Illinois Hospital Association and would like to bring this to the General Assembly next year. Karen suggested that we bring in IDFP and Department on Aging. The DHS, DOORS program was also mentioned along with Rehab services. Some of our sister agencies could partner to increase awareness on websites and through some provider networks.

The members had a discussion the billing options currently for palliative care, which is challenging and not outlined by MCOs. Would like billing to be bundled fee that would include the team in the care of the patient, for palliative services.

Information reminder of 410 ILCS 642 {Exhibit 3}

“Home Health and Hospice Drug Dispensation and Administration Act

No comments.

NEW BUSINESS

Vote Code 280.1020 Licensure procedures per PA 103-0734 {Exhibit 4}

Local county departments exempt from initial and renewal fee.

Voted: Hakeem Bello made the motion to pass, Becky Dragoo seconded. All in favor – none opposed.

Ellen asked what prompted the change. Local health departments did. They were still being surveyed, just not paying the fee.

Proposed Informational Draft bills may impact Hospice {Exhibit 5}

Pharmacy practice act – deliver – advanced directives – training resources POLST Hospice Licensing Act. The Board shall provide data regarding Pediatric Palliative Care. Hospice within department of corrections. Living Will Act – POLST form – Cook County guardians office contradictions sort out who the decision maker will be. All have passed in initial chamber, are in second reading in second chamber. Ellen would assume these will pass this year. Other bill she wanted to mention, will affect hospice and end of life options act – 3rd reading will become a medical aide in dying. 85-95% of those are receiving hospice care.

Board Membership Updates

We do have a full board, minus the 1 representative for Health Care and Family Services. We are still trying to get someone from this agency to make a recommendation.

Public Comments

None

Hakeem asked to see a list of current hospices. The IDPH website has a link to the directories which are updated quarterly. Kristen James asked if there was a way to distinguish peds on this directory in the future. Karen says that we can investigate that. We can try to add it to the application, but it might take a while.

Next Board Meeting Date: August 14, 2025, ● 10:30 a.m.

Meeting Adjourned at 11:37 a.m.