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Hospice and Palliative Care Advisory Board Meeting

November 13, 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=m842edffc241dca54e50e164fd0face46>

Meeting number: 2862 985 2257

Password: mvJ3CwPJq63

Join by video system dial 28629852257@illinois.webex.com

You can also dial 173.243.2.68 and enter your meeting number

Members Present: Susan Fristad, Molly Chapman, Shelly Taylor, Becky Dragoo, Jeffrey Workman, Ellen Byrne, Douglas Irvin

Members Absent: Hakeem Bello, Kristen James, Shawna O'Dell

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

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 10:30 a.m. and announced that this is the Hospice and Palliative Care Advisory Committee Meeting with today's date being November 13, 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.

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.

Approval of Draft Minutes for August 14, 2025, Meeting {Vote} {Exhibit 1}

The draft meeting minutes from August 14, 2025, 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 Becky Dragoo and seconded by Ellen Byrne. With none opposed, the minutes were affirmed and unanimously carried to approve the minutes as presented.

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OLD BUSINESS

Subcommittee Serious Illness update {Exhibit 2}

The subcommittee has been working with palliative care experts to craft some legislation that would establish standards for adult palliative care delivered outside the hospital. We are nearing completion of the final bill of language. We have been in conversation with the State Medical Society, the state Hospital and Health Care Systems Association and there are still some conflicts but the Palliative Care Committee believes that we need to move forward and run this piece of legislation in the spring to make the legislators aware of what we want and to push to negotiate with other stakeholders if we're not quite there with the language. The State Medical Society really wants to put the physicians outside of this bill meaning they don't want the provisions of this bill to apply to physicians who practice medicine in all of its branches. The physicians by themselves do not represent and cannot be an interdisciplinary team. Palliative care services delivered in the community should be an interdisciplinary team delivering with certain training requirements that will be established in the regulation part of the process. There is a role in every palliative care team for the physician as, essentially, the clinical program director. In talking to IHA, the reality is that it's just not possible in some of the rural parts of Illinois and in many underserved areas of the state to have a physician serve as a clinical director would kill this entirely. We would not be able to expand palliative care in the way that is needed in our communities. This does not work in the favor of the physician, and they don't regularly want this type of work. There are exceptions, of course, but it is not typical for physicians to pursue this. Karen asked if there is a removal of the physician as the coordinator, how would we remove them from the rule and what role would they play now? Susan Fristad states that they have physicians involved in the outpatient palliative care, but they don't manage or direct the entire program, but are more of a support to the APN, if needed. Susan thinks it is more of a wording issue. The reality is that there can be physician involvement, but it isn't always the same level for different types of care. Nursing homes will have different involvement from physicians than hospice and hospitals do. It may just come down to perfecting the wording with ISMS. The next step is getting additional recommendations in the language and continue to build support with stakeholders. This bill will be looked at by the Illinois Hospice Palliative Care Organization, as well as the Illinois Home Care and Hospice Council – the two trade groups for home health, home care and hospice.

We've had some interest from representatives, most recently Nicole Grassie, who has experience as a chaplain in hospice care. The information will be introduced in the spring session. Karen asked if we've included assisted living and long-term care. Ellen will be reaching out. Becky Dragoo from Aging noted that we should also reach out to Kelly Richards, State Ombudsman with the proposed legislation. Ellen asked if there was a Department of Aging legislative liaison that she could reach out to. Becky mentioned Bresha Brewer as IDOA's state ombudsman. We took a vote on moving forward with the legislation that we'll continue to negotiate. Motion by Jeff Workman and seconded by Becky. All agreed.

NEW BUSINESS

Discussion on PA 104-0253 Bill 2877 {Exhibit 3}

This bill adds some guidance that the board shall review pediatric palliative care issues as provided in the Pediatric Palliative Care Act. The board shall submit a report to the general assembly on the state of care of individuals experiencing a serious or life limiting illness and their families no later than December 31, 2026. It shall include a minimum of data that we must collect and review regarding the availability of and the need for hospice and palliative services in Illinois, showing the relative value of non-hospice and adult palliative care to our citizens and show evidence-based recommendations to educate health care professionals and public about non-hospital palliative care and recommendations for state standards for adult palliative care. Ellen put together some areas to start from – what to think about, how to collect data, what data we need and where to collect that data from. In other states they issue a FOIA request to the Medicaid office to gain access to data needed to meet requirements, access funds for consulting services to complete the analysis and consider utilizing a third party to assist in completing the analysis and the report. We are open for discussion. We can do another subcommittee but we'll have to identify who will take responsibility with the Department to help put this together. Becky from IDOA asks if this is pediatric and adult or just pediatric. Karen states that the first part notes pediatric care but then it goes through all individual items listing adults so it's a little confusing. Becky would be happy to help with the adult side and work on gathering information from waivers. Ellen notes that there is a template that is available, put together by the Center to Advance Palliative Care, due to the 15-20 states that have created these reports already. There is an existing template to guide the committee through the different sections of such a report and what information needs to go in the report. She also asks if there are opportunities for funding outside of the state because there is no budget for this effort but philanthropic funding from a donor can be directed to pay

for a consulting group or individual with expertise in this situation. We could issue a request for proposal and the funding could come from an outside source. Ellen has contact information for individuals in other states that have gone through this process. Karen asks for a copy of the template and the contact information so that she can reach out to legal to see what avenue we can take. Doug Irvin offered his help and Jeff Workman, as well.

Discussion of End of Life Options SB 1950 {Exhibit 4}

This bill has been passed through both Houses, but the Governor has not signed it yet. If it does get signed, we will need to consider what, within our rules, that this would impact. Obviously, it is going to impact others, not just hospice. The person must be 18 years of age, have a terminal illness, will have to make two oral and two written requests for the dose or dosages. It must be witnessed by someone, and they must self-administer the medication. We want to hear everyone's thoughts on this and see, once it does get signed, what to look at implementing within our hospice program. Jeff asks how this will impact payment, medications, consulting, etc. Are the hospices responsible for the payment? Ellen responds that, because of the HIDE Act, which is federal legislation, hospices are not allowed, even if the hospice medical director would be the one to issue the prescription, that no federal dollars can go to someone ending their life. A hospice could not cover the cost of the lethal medications that the patient would be taking, unless they did it through charity care. It can't occur in an inpatient unit and hospices cannot bill for the day of the death when the patient takes the medication. It doesn't mean they can't see that patient, but they cannot bill for that day. Ellen has been talking with the hospice providers over the last 10-12 months and their education specialist has a lot of slides and information. We have been in contact with several other states who are already doing this. We are the 12th state.

The effective date of legislation is 9 months after it is signed into law. There was some discussion regarding this being too soon to get rules approved. It was also mentioned that some medical directors who may be very religious individuals would not be forced into a situation. A hospice organization cannot force an employee to participate in any way. Conversely, if the hospice organization was religiously oriented, and did not want to play a part, an individual medical director could still participate outside of their employment. We will have to be very clear in our rules.

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

Board Comments

Ellen had another topic to discuss. Effective October 1, 2025, hospices all had to switch to a new quality measure tool called the HOPE tool and according to the CMS guidance document, there is a type of follow up visit that is required when a patient has a symptom that is impacting them in either a moderate or severe level. There is an admission visit, and two hospice evaluation visits required. They're called HUV (Hope Update Visits) visits that occur in the first 60-day period. If during one of their assessments, done by a nurse, it is identified that they have a symptom affecting them in this way, the follow up is then required, by either an RN or LPN. There has been some pushback in certain cases. The guidance says very specifically that this is not an assessment so this symptom follow-up visit, would it be viewed as an assessment? We want to make sure that the State of Illinois is ok with following the CMS guidelines and allowing an LPN to do these visits. Karen asked Ellen to send her the information so that she can take a look at the scope of practice. Becky might also be able to take a look at the sub-regulatory guidance. We can bring this back to the next meeting.

Next Board Meeting Date: February 19, 2025, ● 10:30 a.m.

Meeting Adjourned at 11:30 a.m.