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Hospice and Palliative Care Advisory Board Meeting

August 14, 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=md08896d9b2286434fcdbc7d6af352bca>

Meeting number: 2634 051 9239

Password: EAcQj6JTt22

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You can also dial 173.243.2.68 and enter your meeting number

Members Present: Kristin James, Hakeem Bello, Susan Fristad, Molly Chapman, Shelly Taylor, Becky Dragoo, Paul Hutchison, Doug Irvin, Jeffrey Workman, Becky Dragoo

Members Absent: Ellen Byrne, Shawna O'Dell

Department Staff: Karen Senger, Jackie Richmond, Rebecca Gold, Stephanie Glenn

Guests: Stacie Sinclair, Associate Director at Policy and Care Transformation at the Center to Advance Palliative Care
Nicolle Grasse, State Representative

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 August 14, 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.

Approval of Draft Minutes for May 8, 2025, Meeting {Vote} {Exhibit 1}

The draft meeting minutes from May 8, 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 Doug Irvin and seconded by Kristin James. With none opposed, the minutes were affirmed and unanimously carried to approve the minutes as presented.

OLD BUSINESS

Subcommittee Serious Illness update {Exhibit 2}

Doug Irvin filled in for Ellen Byrne giving the update. The committee recently spoke to the Illinois State Medical Society and some initial suggestions were made and some are forthcoming after some of their representatives meet internally. We will meet again when we've reviewed all the suggestions. We primarily answered questions about the intent of the legislation, why it is needed, why we utilized the Alzheimer's Disease in Related Dementia Services Act as a model for the legislation and expressed that the primary issue is ensuring that the standards apply to all care delivered outside of the hospital and how to include physician practices, which were explicitly excluded by the Alzheimer's Services Act. So far, the feedback received questions the two definitions of palliative care – one that exists in the pediatric palliative care legislation and a potentially different one in whatever might be carried forward out of the subcommittee work. The IL State Medical Society was concerned about setting standards that could have a negative impact on the provider's willingness to provide services and ability to make the care accessible statewide. We want the applicability section to apply if the facility is providing palliative care, if this is in a facility location or if they contract with an entity that provides palliative care. We need to make sure that we cover home grown as well as brought-in services and that the entity and the place of care are both covered by the definition and the state medical society agrees that they will try to help with this. The standards for provider entities section needs simplified language using reference to state licensure. The IL State Medical Society would like to understand what the oversight mechanism will be, if it's not licensure. Would an attestation that this was being reviewed during a survey work for that? What about an outpatient medical practice and survey environment for that and whether there is oversight for it? Does anyone have any input. Karen stated that she was also wondering how that was going to work, as we don't regulate or license independent physician clinical practices, so not sure how that oversight was going to work. Becky Dragoo agrees that there should be some oversight, since there is for every other provider type. She doesn't have the answer at this point, but we need to look into it. Karen asked if the Medical Society had any suggestions? Doug said that they are also kind of in the same spot at the moment – just not sure how to proceed. Karen asked if they also met with IHA? Doug says that they haven't met yet but they are working on feedback and planning to meet when we get more feedback. He asked for any help. Karen said that she could reach out to her contact there.

Some other open questions here are about defining an appropriate population, whether prognosis is involved or is unspecified, especially around time frames. Hospice has a clear time frame but trying to decide if palliative needs a time frame, the conversation gets awkward. If we are able to pass a bill in 2026 that becomes law in the summer, what is a reasonable date to require IDPH publishing rules? That's an open question here. Karen stated that usually you don't put a specified date in for the rules to be written by, by we generally would have a year. The last open question was about the standards and provider entity section, around social work involvement. Will all interdisciplinary involved social workers be Master's prepared clinical social workers or licensed social workers who have the right credentials for social work involvement? We've been trying to balance the credentialing of involved parties with the more credentials required, the harder it is to assure that the availability of those credential could be limiting the availability of the service. For example, if we said that only physicians who have fellowship trained credentials in Hospital palliative medicine, will the pool of available participants get extremely small? Representing a hospice as an operator, I can say that our difficulty in hiring the appropriately credentialed social workers of hospice is hard enough and the by diversifying that responsibility into this provision, it could shut down the ability to include social workers, potentially. Becky noted that, in governing home care, we do offer some consideration and waivers of the credentials for work experience. Karen agreed with Becky and with Doug about the difficulty of hospitals getting those social workers.

NEW BUSINESS

Information House Bill 2877 {Exhibit 3}

This bill has not yet been signed into law yet by the Governor. The board shall submit a report to the general assembly on the state of care for individual experience at a serious life-threatening illness and family caregivers reports will include data on availability and need for hospice and palliative care services, data showing the relative value of non-hospital's adult palliative care, an evidence based recommendation to educate care professionals. This is something that we will need to implement and should talk about at the next meeting. We don't want to move forward until it is signed so at this point, it's just something to think about. We will have a formal discussion at the next meeting.

Presentation – Stacie Sinclair, Associate Director at Poly and Care Transformation at the Center to Advance Palliative Care {Exhibit 5}

We are a national healthcare care non-profit that is dedicated to ensuring that everyone living with serious illness has access to the high-quality palliative care that they need. We have worked on the serious illness scorecard with is a national report to better understand what they landscape of serious illness is and also supplemented that with some individual state reports. The US healthcare system is not set up to meet the needs of patients and families living with serious illness, per Amy Kelly's definition, which is a health condition that carries a high risk of mortality and either negatively impacts the person's quality of life or daily function or excessively strains their caregivers. Our best estimates, and this is likely and undercount, is that there are at least thirteen million adults and approximately seven hundred thousand children living with a serious illness today. There is often a misunderstanding of communication of prognosis with clinicians on what to expect with their illness, the treatment value and treatment decisions not being informed by patients' goals and values. Pain and symptom management is often more reactive than proactive and the data shows that pain and other symptoms drive the majority of unwanted and often unneeded emergency department visits. All of this comes at a cost to the wellbeing of our family caregivers. What we would like to see is a more proactive system that has regular screening management of symptoms and other sources of distress for every patient living with serious illness, and much better communication with the patients and their families and more support for caregivers. There is also a disparate experience of care, quality of care based on a number of factors, including race and ethnicity among others. There are a couple of data points pulled from some research that CAPC (Center to Advance Palliative Care) did recently. First, we looked at the experiences of black, Hispanic and Latino patients. We saw a higher percentage of black and Hispanic older adults reporting that they've never had their preferences considered. Also, a significantly higher number of black and Hispanic patients who report having more than one emergency department visit in the last month of life, even one year post diagnosis.

In the previous state report card, which is a product of CAPC and the National Palliative Care Research Center (NPCRC), dated 2006, there was not a lot of information about palliative care available as this was a brand new field. So, what CAPC and NPCRC did was work with the American Hospital Association to collect a single metric which was the prevalence of hospital based palliative care programs in each state. We looked at the number of hospitals with fifty or more beds that reported to the American Hospital Association that they had a palliative care program. We looked at the prevalence and converted it to a letter grade and began to compare access to palliative care. We did four additions between 2006 and 2019 and this was a real success story for us because what we saw was that inpatient palliative care access had grown dramatically and the number of states with A's and B's went up significantly. We were able to pull in more background information of what palliative care is in the front of the report and have policy recommendations in the back. Every time we released a new edition, we also saw the grades going up and increasing recognition. It feels like a big win!

We talked about doing another addition but noticed that numbers were leveling off and the majority of large hospitals reporting having palliative program now extends well beyond the four walls of the hospital and into the community. We wanted to take some time and reconsider if there was another way to tell the story. We came up with a new serious illness scorecard which looks at each state's capacity to deliver high quality care to people living with serious illness. We now have 10 variables across 5 domains that we consider to be important things to look at in the conversation. The five domains are:

1. Specialty Palliative Care availability
2. Payment for Palliative Care services
3. Structured champions, advocacy and support
4. Building skills outside specialty Palliative Care
5. Foundation for functional and caregiver support

How did Illinois perform in 2024? The state got a 4 out of 5, which is actually a very high score in this measure. There is a score chart showing how Illinois performed, which is available on the scorecard website. The largest health insurance provider was Blue Cross Blue Shield, and we did not find that they had unique services for serious illnesses. We want to congratulate you for the work that you've done, and the time invested. We tell all of our high scoring states that your work has been reflected well but there's always more work to be done.

In addition to revising the new scorecard, we also updated our individual state reports to provide everything that we could find in a standardized way at the state level. We are continuing the work of exploring additional Medicaid reimbursement for community based palliative care in the adult population. Illinois is a leading state due to the work that you've done to establish loan forgiveness for palliative care and hospice professionals. I have

a list of recommendations, activities that some other states have done, for consideration. One state has developed optional modules to incorporate in its behavioral risk factor surveillance system.

One of the reasons that we decided to work on the new scorecard is because palliative care has moved out of the hospital and into the community. One way that we can track these new programs is through getpalliativecare.org provider directory which is a self-report directory, free to any program that wants to be listed.

A big reason that certain states scored highly on the scorecard is that they had meaningful coordination across all interested parties making sure that different voices were being represented in helping understand what the gaps are and what to prioritize. The majority of states do not have the resources.

The Board thanked Stacie for her presentation. Becky noted that she would reach out soon regarding the multi sector plan for aging, an executive order signed by Governor Pritzker last year. She might ask that Stacie present this to other groups.

Stacie will follow up with Jackie to provide a copy of her slides, to send out to everyone.

Hospice Facility Number and Survey Data {Exhibit 4, 4a}

Exhibit 4 shows the numbers of where we are at for the last year. Exhibit 4a is the database for deficiencies, in order of most cited tags.

Hospice statistics: 174 licensed agencies as of 6/30/2025. 151 are licensed and Medicare certified. 23 are licensed only. 99 are deemed/accredited. 8 are Medicare certified in a bordering state. 10 are licensed as hospice residences. The number of hospice complaint investigations received from 1/1/2024 to 6/30/2025 was 28. 13 were investigated, 8 were substantiated (2 COP, 4 Standard level deficiencies) and 5 were unsubstantiated. The COP was 1 organization administrative services, 2 drugs, biologicals, medical supplies and DME.

There were 21 recertification surveys conducted on non-accredited hospices. There were 16 initial hospice licensure surveys, and 1 initial hospice residence. There were 14 annual licensure surveys for hospice residences.

The most cited deficiencies were: violation of plan of care, counseling services, content of the comprehensive assessment, and not all being complete on criminal background checks.

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. Jackie reminded everyone that she recently sent out an email regarding some mandatory annual training due at the end of September and if there were any questions to reach out.

Public Comments

None

Other Comments

Becky had a question about the medically fragile children about the status of the quest to receive Medicaid reimbursement under the Medicaid waiver? Molly stated that she didn't have an answer at this time but it's a really interesting question. It would mean that it would have to be added as a waiver service.

Nicolle Grasse, State Representative, stated that there are great concerns with the proposed cuts to Medicaid and how it will affect our state. She asked if there was any data on the cost savings of accessing Medicaid for palliative care or how it will be a financial benefit to have this available to people. Karen was not aware of any data at the moment. Becky thanked Representative Grasse and said that she posed a great question. She is going to have the research staff look into any data from other states. Doug will also check with Ellen to see if she can get the information.

Jeffrey asked if there has been any movement on the billing for room and board through the nursing home for hospice patients. Representative Grasse recently brought up that issue with several people and it seems that this is a federal issue, so we need to get people to lobby for it. Doug mentions that it's unlikely to change, as it's codified in the Social Security Act, but there are other resources to assist through the state hospital, the Illinois Hospice and Palliative Care Organization has a reimbursement work group.

Next Board Meeting Date: November 13, 2025, ● 10:30 a.m.

Meeting Adjourned at 11:36 a.m.