



APPROVED MEETING MINUTES
Hospice and Palliative Care Advisory Board Meeting
August 8, 2019 - 10:30 a.m. – 12:30 p.m.
Video conference locations:
525 W. Jefferson, 4th Floor, Springfield
122 S. Michigan Ave, 7th Floor, Room 711, Chicago
Bellwood Location is Not Available for this Meeting

Call to Order

Members Present: David Lockhart, MD, Susan Fristad, Nancy Flowers, Shawna O'Dell, Shelly Taylor, Pamela Cramer, Irene Kelly Fischer and Daniel Holste

Members Absent: None

Department Staff: Karen Senger, Elaine Huddleston, Beena Varghese, Edward Pitts, and Siji Varghese, and Staff Attorney, Junaid M. Afeef

Guests: Rachel Naffziger, Kelly Garcianone, Kristin James

Introduction of Committee Members and Guests

Karen Senger called the meeting to order at 10:33 am with an introduction of Board members, Department Staff and guests. A quorum was not established at this time, and the Board agreed to wait a few minutes for additional Board members that were on their way to one of the meeting locations. Board member, Shelly Taylor arrived later at around 10:48 am, and a quorum was established at that time.

Approval of Draft Minutes for May 9, 2019 Meetings

The draft minutes of the May 9, 2019 meeting was reviewed and discussed by the Board. A motion was made to approve the minutes with minor corrections noted, 2nd and a motion was unanimously carried to approve the minutes as presented.

OLD BUSINESS

Board Approval Regulation Changes:

Karen Senger presented this section to the Board in regards to changes to the proposed draft changes to Part 280 of the Hospice Programs. Board members were give a copy of the proposed draft changes and covered the following sections as follows:

Section Code: 280.1010 - Incorporated and Referenced Materials;
Pages 2-5; updated the following Incorporated and Reference Materials and Federal Regulations to this section;

Section Code: 280.1020 - Licensure Procedures;
Pages 5-9; noted minor grammatical changes;

Letter i) – Change of Ownership or Sale – biggest change to the rules was to this section and language written mirrored Home Health Regulations on CHOWs;

Section Code: 280.1030 - Statement of Ownership;
Pages 9-10; noted minor grammatical changes;
Letter b) – changed the number of days from 10 to 30 days that the licensee shall notify the Department of any change in information required in the paperwork before the change occurs;

Section Code: 280.2010 - Hospice Services;
Pages 10-14; noted minor grammatical changes;
Letter a) 7) F) – Alzheimer’s Services (page 13) – addition of this section referenced Hospice program to provide Alzheimer’s disease and related dementias services in accordance with the Alzheimer’s Act and Code.

Section Code: 280.2040 – Personnel Policies (pages 14-16);
Letter e); (page 14) addition of language to include training in Alzheimer’s care in accordance with the Alzheimer’s Rules Code 973.

Section Code: 280.4010 – Licensure of Hospice Residence;
Pages 16-18; noted minor grammatical changes;
Letter a); (page 16) – changed the number of licensed hospice residence from 12 to 15;
Letter d); the number of Licensure category changed and the break out of the changes to the categories were noted.

Section Code: 280.4040 – Hospice Residence Operational Requirements;
Pages 19-23; noted minor grammatical changes;
Letter e) – Physical Plant Requirements; noted the new NFPA 101 requirements listed under the current Code;
Letter e) 13) – Hospice residences change in patient beds from 16 – 20.

Karen Senger ask if there were any questions or comments to the proposed Rule changes. No one had any comments or questions. A motion was made to approve the proposed rules with minor corrections noted, 2nd and a motion was unanimously carried to approve the proposed rules as presented with changes.

Review of Alzheimer’s Disease & Related Dementia Service Code 973

Karen Senger presented this topic to the Board. A copy of the approved Alzheimer’s disease and Related Dementia Service Code 973 were given to the Board and asked if they had any questions or comments. Karen Senger commented will draft a memo from the Department and send out information in regards to the required training to the Agencies on these rule changes. The Board was informed that the training information has not been uploaded on the website at this time and will be working to get them posted.

A question was asked in regards to Staff Training, Section 973.140 of the Administrative Code if the Department will be sending this information to all providers (Home Health and Hospice) and would there be a definite date and time to complete the training by. Karen Senger commented will be sending a Memo to each provider that will outline the requirements and examples of the training curriculum that can be found on the IDPH Website. This training requirement became effective as of June 2, 2019 in that staff with direct access to clients with dementia receive advanced training and the Department will look at meeting this requirement when the Department is conducting the facilities annual survey.

A comment was made that there is resources out there for free Alzheimer’s training provided for non-members of Organizations to meet the training requirement. Karen Senger commented that the Agency needs to focus on patient population and that managers need to be thoroughly trained as well. The curriculum and training is outlined in the rules under letter “e”. A question was asked if voluntary

employees are required to complete this training. Karen Senger commented that voluntary employee's falls under letter "c" of the Code under the definition of staff with direct access to clients will need this training. Facilities should expect to receive a copy of this memo in the mail and by email with their license renewal notification.

Palliative Care Language

Board members were presented with a copy of a definition that was put together and approved by the Subcommittee and presented to the Board for review. The Board agreed on this version of the definition on the means of what Palliative care means.

The Board shared some of their concerns and comments on the definition that is currently listed in the Hospice Statue Language and Administrative Code. A consensus was made that the Hospice Statue is pretty vague on the definition, and would like to elaborate on the definition listed in the Administrative Code to a broader definition of Palliative Care. The Board was reminded that the Statue will need to be changed first and then adjusted in the Rules and then post on the IDPH Website.

The Board agreed that the Department is limited with resources with the Director to change the definition in the Hospice Statue. The Board will need to reach out to an Association or Organization to connect with and help facilitate and sponsor to replace this definition in the Statue.

Psychotropic Medications

Karen Senger presented this topic to the Board. A question was brought up if the Department has heard anything back from IDPH-LTC Section on PRN of Psychotropic Medication administered to Hospice Patients in Nursing Homes. Karen Senger commented spoke briefly with Connie Jenson, Section Chief of LTC on this ruling, and she shared that this is not mandated. Board members shared that the problem is with the LTC surveyor staff when they survey the LTC Facilities on a statewide issue.

Karen Senger commented will have to work with the LTC counterpart over the LTC Surveyor staff and suggested that the Board take a different route and bring the topic to the LTC Board directly. She will need to reach out to this Division and get added to their Meeting Agenda to address the specifics at their next meeting. Karen Senger ask the Board to put something together and send her a one page document to cover some issues and concerns to address the problem to present to the LTC Board. Also, would like for a Hospice Board member to go with her to the next LTC Board meeting to present this concern to their members.

No other comments were made.

NEW BUSINESS

Hospice Statistics Jan-July 2019

Karen Senger presented this topic to the Board. A handout was given with a brief overview with statistical comparison given regarding the number of facilities and number of complaints received, and the types of allegations for complaints received during the time period of January 2019 - July 29, 2019. There were 8 complaints investigated from January to – July 29, 2019 that included 4 substantiated and 4 unsubstantiated.

A category report was given with a break down on the number of recertification surveys conducted with the number and types of tags cited and hospice agencies that are licensed through the period of January to July 29, 2019.

A brief comparison with the number of standard tags that were cited during surveys conducted was given for the period of 2014 – August of 2019. This report also listed surveying tags for Emergency Preparedness (EP). These tags were listed on the last page of the report with no major issues noted.

Karen Senger further commented that this review/comparison also gives the Board a brief history of the types of allegations and number of tags cited during this period for informational purposes. The number and types of Standard Level Violations were also included in a table/graph format for the period of 2014 – August of 2019. Karen Senger commented that she hoped this will be more beneficial and will try and bring this type of reporting to the Board every six (6) months for better comparison for the Board to review. The goal is overtime this data will reflect a norm of deficiencies cited to list information to help assist the Board to see what the Department is finding during their surveys.

No other comments were made to this report.

Presentation Pediatric Palliative Care

Kristin James, GIPPCC Executive Director of Greater Illinois Pediatric Palliative Care Coalition (GIPCC) presented this topic for discussion on how we care for Home-Based Pediatric Palliative Care for children and their families. Her presentation included how this group has had the opportunity to work within Illinois and expand the options for pediatric palliative and hospice care for children.

This group has started to develop a list of Adult Hospices that have already been identified as having a team trained to care for these children. This list has increased from 9 to 14 Hospice facilities that now care for Pediatric Palliative Care Children. They are working to reach more Hospice and Home Health teams to assist in increasing access to home-based care. The group is also wanting to try and work with other teams to increase awareness and help educate various Hospices, Home Health's and Medical staff on the care for Pediatric Palliative Care for Children.

This group has been fortunate to have worked with various legislators over this past year to help sponsor a bill (SB1105) to support a state plan amendment for Home-Based Pediatric Palliative Care Program. The original bill, 305 ILCS 60/Pediatric Palliative Care Act was signed into law in 2011, but was never funded. They were able secured appropriations from Department of HFS to work with GIPPCC to explore a delivery model for pediatric palliative care. They are eager to partner with Legislation and other State partners to help look at developing a plan with lowering cost effectiveness for this services and help families find facilities that are able to help with Hospice Care and are closer to home.

Karen Senger commented that the Senate Bill (SB1105) did not make it through at the last minute. The Department partnered with Department of HFS to tried to push this Bill through and at the last hour was unable to get it approved with Department of HFS and was never funded. She will try and bring a copy of the Rider from 2009-2010 to share with the Board to help devise a state plan and look at State of Illinois and other states on this concept.

Kristen James commented they have offered and hosted 11 regional trainings to various Hospices to help the Health Care givers learn how to care for these Children in order to help keep these kids/children closer to home and in their own community. We feel this is the right thing for Hospices to do and to also help support the families of these children. Other Board members share some of their concerns on about how 50% of Hospice facilities do not provide Kid Care and do we even have the resources to accomplish this task.

Karen Senger responded yes and no. We need to look at the State level to help account for some resources and for greater support to help make this program happen. The need for this type of care is growing and so is the need to train the Health Care system such as Home Health and Hospices to be confident in taking care of these children and to provide the resources needed to the families.

Several other concerns shared were on how caring for Children in the State of Illinois that are in Hospice Care is down about 10% and how there seems to be a stigma of fear and emotions and this type of care is foreign among care givers. The interest is we need to develop a way to provide some kind of training to help care givers feel more comfortable and to be prepared in taking care of these children and helping the families in their community. The training also needs to help with the process of bereavement.

Karen Senger commented the Department has a Directory listing of licensed Hospice Agencies that the Department surveys these entities that provide or handle Hospice care for pediatric children that staff can benefit from this training. She will provide a copy of the IDPH Directory of licensed Hospice facilities to the Board.

No other comments were made.

Coalition

Karen Senger gave a brief update on state Palliative Care activity updates that was shared with her from Staci Sinclair, MPP, LBSW Senior Policy Manger with Center to Advance Palliative Care for informational purposes to name a few:

1. The National Coalition for Hospice and Palliative Care publication of the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care, 4th edition* NCP Guidelines.
2. Review of the NCP guidelines found on the following link: www.nationalcolitionhpc.or/ncp.
3. Use the NCP Guidelines to inform any policy-related activity to ensure changes are consistent with the guidelines.
4. MACRA Measure Development Project
5. NASHP Palliative Care Policy Summit
6. Palliative Care and Hospice Education and Training Act (PCHETA)
7. Miscellaneous Notes and Reminders

Board Membership Updates

Karen Senger presented this section on Board Membership;

- a. New Members: None to introduce at this time:
- b. Membership vacancies:
 1. One (1) position for Member Recommended by Advocates on behalf of Hospice Patients & Families vacated by former Board member Ronette McCarthy; resigned effective 5/30/17; pending nominee approval by the Director's Office.
 2. One (1) position appointment by HFS Director for replacement of former member Aimee Isham – resigned effective 11/1/2018; nominee none.
 3. One (1) position appointment by DOA Director for replacement of former member Jamie D. Ewing – resigned effective 05/2019; nominee none.
 4. One (1) position appointment by DHS Director for replacement of former member Michelle Eckhoff – resigned effective 05/31/2019; nominee none.
- c. Membership Reappointment pending approval by the Director's Office:
 1. One (1) position for member from Hospice Programs for Board member Nancy Flowers; term expired 05/19/19; pending IDPH Director's approval.

Karen Senger commented that we are still waiting to hear back from the Directors for names of nominees for replacements of representatives from these State Offices (HFS, DOA and DHS) for their respective Divisions to serve on the Board. In addition, these three vacancies are from our sister Agencies, and after review of the Bylaws, they are counted as non-voting members and are not included in establishing a quorum.

Dr. Lockhart commented that he is officially retiring later this year, 2019 and will no longer continue to serve on the Board unless the Department is okay with him continuing. He can nominate a Licensed

Physician that can finish his term out since it expires next year. Karen Senger congratulated him on in his retirement plans and thanked him for his support and expertise he has given the Board. Karen Senger also commented that Dr. Lockhart would be able to finish out his term, which does not expire until April, 2021.

Travel Mileage Reimbursement

Board Members were provided a blank travel voucher-mileage expense form (effective: 01/2019). Board members were reminded to complete the current mileage reimbursement form and were instructed to submit their completed travel expense forms to IDPH, staff Elaine Huddleston for processing or with any questions.

Other Comments

Karen Senger commented that going forward at the end of discussing meeting Agenda Items, the meeting will then open up the floor for additional comments by Board members and the public for additional comments.

Dr. Lockhart presented this topic on advanced directives with frail elders. He had put a seven minute video together to share with Board members to help promote a conversation on this topic, however, the video was not able to be shown during the meeting. The purpose of this topic was over the statistic of the number of elder patients die at home (75%) or die in the Hospital (75%) and how elder patients are not aware of this process or talk about their choices (Advanced Directives).

A comment was made about how family members are not familiar with or understand the DNR (Polst) form and patient's final wishes are not met. A discussion was covered on how family members are making the decision for the elder patients and not having a conversation with the elder patients on their final wishes. Dr. Lockhart commented will email the link to this video to Board Members on this topic.

No other comments were shared.

Meeting Schedule

1. Meeting Schedule for 2019

Karen Senger reviewed the remaining meeting dates for 2019 that have been established for informational purposes. The Department will be sending an Outlook meeting invite for the remaining meetings for 2019. Board member were reminded to mark their calendars and make note of the meeting times and locations as not all meetings will have the Bellwood location available.

2. Meeting Schedule for 2020

Members were given a copy of the meeting schedule for 2020 for informational purposes. Members were asked to mark their calendar accordingly and plan to attend.

Next Board Meetings:

1. November 14, 2019 • 10:30 a.m. (122 S. Michigan Avenue, 7th Floor, Room 711, Chicago, 525 W. Jefferson Street, 4th Floor, Springfield). **Bellwood Location is not available for this meeting.**
2. February 13, 2020 • 10:30 a.m. (122 S. Michigan Avenue, 7th Floor, Room 711, Chicago, 525 W. Jefferson Street, 4th Floor, Springfield). Bellwood Location is pending availability for this meeting.

Meeting Adjourned at 11:50 am