



ILLINOIS DEPARTMENT OF PUBLIC HEALTH
OFFICE OF HEALTH CARE REGULATION
DEVELOPMENTALLY DISABLED FACILITY ADVISORY BOARD MEETING
May 9, 2018 • 10:00 AM – 12:00 PM

APPROVED MINUTES

I. CALL TO ORDER AND INTRODUCTIONS

Connie Jensen facilitated the meeting. The meeting was called to order at 10:04 a.m. and introductions were made.

MEMBERS PRESENT: Deborah Kennedy, Michael (Mike) Bibo, Jeff Stauter, Dr. Geunyeong Pyo, Lois Sheaffer-Kramer, and Fabricio Balcazar

MEMBERS NOT PRESENT: Nancy Andrade, Susan Fonfa and Dale Simpson

IDPH REPRESENTATIVES: Connie Jensen, Sean Dailey, Daniel Levad, Sherry Barr, Pamela Winsel, Lisa Griffith, Michelle Millard, Debra Bryars, Darlene Harney and Tena Horton

GUESTS: Bill Bell and Marie Rucker

A quorum was established.

II. APPROVAL OF MEETING MINUTES

The drafted meeting minutes for February 7, 2018 were reviewed. A motion was made by Mike Bibo to approve the minutes as presented, seconded by Lois Sheaffer-Kramer. Voted unanimously. Minutes were approved.

III. MEMBERSHIP UPDATE

A. Membership Vacancies:

- (1) Physician Member
- (1) Resident Advisory Council Member
- (1) Nancy Andrade resigned the position of Public Member
- (1) Susan Fonfa resigned the position of IL Department of Healthcare & Family Services

Connie Jensen asked the Board to assist with filling the vacancies for the Board.

B. Expired Terms – N/A

IV. OLD BUSINESS

A. Informed Consent (IC) for Psychotropic Medication Form Discussion:

1. Dr. Balcazar had a question regarding the Wisconsin Informed Consent. He wanted to know what was the outcome or final decision and if the Board is going to utilize the Wisconsin IC for informing people about their medication. Connie Jensen informed Dr. Balcazar that the IC was discussed and the Department was going to review. Any recommendations that were made by the Board, the Department would take under consideration and move forward with the IC. There was no decision if it would be specifically the Wisconsin IC. Mike Bibo wanted to know if the Department is going to proceed with the IC issues/forms and inform the Providers Union, or will it be back to the Board. Connie Jensen asked what was the Board's opinion with the IC? She stated that Long-Term Care Advisory Board had moved it out as the Department had taken all of their considerations. Again, she asked if it needed to be brought back to the DD Advisory Board for further discussion? Mike Bibo stated that it would depend upon what action the Department would take. He also stated that the Board has a right to request the fiscal impact of it as there may be fiscal impact which will depend upon the direction of the Department. Therefore, it may need to be reviewed again. Darlene Harney informed the Board that the LTC Advisory Board voted to consider the form that Dr. Maurer presented and had a very lengthy discussion. Darlene asked if it was something that Mike Bibo is considering. Mike Bibo's concern is that one has the right to issue an informed consent form. But, the way the Act is written on both the IDD Community Care Act, the Nursing Home Care Act, and possibly the MC/DD Act, it states that the population of the form to indicate the risks is the Department's responsibility to provide this information on a website form. To sign just a blank form in which Dr. Maurer presented allows for a format. But, the Act indicates short of individuals putting the demographics, all side effects and implications of a drug are to be completed by the Department and be available on the website for their access.
2. Mike Bibo indicated that it is hard to have a discussion when you do not know what the Department is proposing. Connie Jensen stated that there should be further discussion identifying the form, how it is intended to be used, and then have that discussion with both LTC and DD Advisory Boards. Mike Bibo stated that this is the way he sees it according to the Act. Darlene Harney also stated that the Department would have to have Legal's input, as well. She also stated that George Logan made comments at the LTC Advisory and what he interpreted when reading the Administrative Rules/Act. Connie Jensen informed the Board that George Logan was not available today, and therefore, the Board will need to have George Logan available for the further discussion.
3. Connie Jensen stated that there should be a discussion on Mike Bibo's statement of "fiscal impact of the form" and/or the impact of the form and implication for use. Mike Bibo stated that there are no fiscal impacts on the serious incident action report and that it was just a format that was being promoted that they used. Depending on this, as part of the IDD Community Care Act, the MC/DD Act, and the Nursing Home Care Act, the Board has the right to ask on any regulation what the fiscal impact would be which would be inclusive of the forms being mandated. Connie Jensen questioned was it meant that "the time it is going to be involved in filling out the forms, physician time, nurse time, etc". Mike Bibo indicated "yes".

4. Connie Jensen asked Dr. Balcazar if the discussion helped clarify as to where the Board is headed regarding the IC? The IC will be brought back to another Board meeting for further discussion. Dr. Balcazar stated “No”, it was discussed that it would be presented as a best practice for the State Act practices so it is very helpful for the State to follow. Dr. Balcazar stressed that is a very important to follow through.
5. Dr. Balcazar had a comment regarding a Public Member and wanted to know if the Department is going to reach out to an organization or association (i.e., AARP) to identify a Public Member. Connie Jensen inquired if the Board is open to suggestions and if anyone has an idea or know of someone who would like to submit an application. Connie Jensen suggested that Dr. Balcazar submit the information in writing to Tena Horton, Acting Board Liaison. The Department will pursue the application. Mike Bibo commented that the AARP would not be appropriate for the DD Facility Advisory Board as the Board has a different age group they serve. Dr. Balcazar clarified that he said ARC and not AARP.

V. New Business

A. Rulemaking – Part 390- Incorporating PA99-180 which created the MC/DD Act and Repurposed the Under Age 22 Facilities as Medically Complex Facilities:

1. Sean Dailey advised the Board that Subpart A is largely technical changes having to do with implementing the new MC/DD Act. It’s updating statutory language and repealing a couple of sections that are obsolete. It basically goes through most of the section of Subpart A and bringing them up-to-date and complying with the requirements of the new Act. All of the information was extremely out of date as Part 390 had been under the MC/DD Act and never received the necessary changes back then. These changes were long overdue.
2. Lois Sheaffer-Kramer had a couple of technical issues on Page 9, Section 390.110. Under A, there still is the language of “under 22 years of age”. Lois would like to propose to strike that information as it is the very issue that has been in the way of admitting people who are medically fragile and over the age of 22. Can the Board just cross out “under 22 years of age” and have it read “provide nursing care to persons pursuant to the terms and conditions of the MD/CC Act. Sean Dailey asked “can these facilities only admit persons under 22; (knows they serve people over 22)”? Mike Bibo stated that when the Act was rewritten they deleted the Acts requirement that it be under 22 and it was basically in the title. This was due to persons over 22 who have critical care needs and they did not want them sent to a Nursing Home. This would allow persons to remain in the facility in which they have grown up or moved in. Sean Dailey agreed to strike the language.
3. Lois Sheaffer-Kramer also identified a couple of technical or typographical errors. On Page 27, Under D, change to reflect a semi-colon. Sean Dailey indicated it was a strikethrough and will reflect a common. Also on Page 34, Section 390.270, Under A, the bottom number should be six (6) and not seven (7). Sean Dailey will correct.
4. Deborah Kennedy had a comment on Page 11, Section 390.120. In the first sentence, it seems like something is missing and is not sure why we are not using terms that are disability friendly versus the first language of “an individual with a disability”. The sentence as it reads appears that there is something missing. “Application for a license to establish or operate a medically complex for the developmentally disabled facility shall be made in writing”. Mike Bibo stated that the first

letter of each word in that starting with medically complex for the developmentally disabled should be capitalized as it is the title referred to in the MC/DD Act. Sean Dailey stated he utilized the words as it is spelled out in the title of the Act. He stated that the statutory language “application to operate a facility” was to clarify that it is a MC/DD facility. He can upper case the wording, but JCAR may put them back to lower case. There is no guarantee. Sean also stated that he would put the acronym after the title, per a Board member’s suggestion.

5. Unrelated to the document, Dr. Balcazar wanted to know if the Agency has enough resources/personnel currently to oversee of these policies? As good as the policies may be, if they are any resources in the State to oversee and assure compliance, then there will be an issue. Lois Sheaffer-Kramer stated that she can assure that facilities are being monitored. Connie Jensen clarified that the Department does have a licensing body, surveyors and ongoing survey processes that routinely survey and enforce the rules and regulations relating to these facilities. She stated that the Department has onsite surveys on an annual basis with these facilities and as well as complaint investigations, or as needed. Connie Jensen informed Dr. Balcazar that the changes were just in the rules (i.e., names and updating). Regarding the survey process, the Department conducts routine surveys.
6. Connie Jensen asked for a motion to move the Part 390 updates forward as amended. Lois Sheaffer-Kramer to move forward and seconded by Mike Bibo. Voted unanimously. Amendments were approved.

B. Rulemaking – Part 390- Amends the Notice of Violation Timeline and Definitions Section:

1. Sean Dailey stated that in Section 272 in letter (e) the information was out of date and needed to be updated to the current deadline for the Department to issue notice of violation. The rest of the Section was cleaned up. Last Winter of 2017, the Department had the Part 390 in JCAR for the Social Security Amendments and are now removing the Social Security numbers requirement from the licensure applications. JCAR noticed that the definition of Act in the Definition Section still said nursing home care. JCAR was displeased about this oversight. Therefore, an agreement was reached in order to adopt these amendments, and upon resubmission of amendments for Part 390, the Department would have to update the definition for Act to the MC/DD Act. Sean stated he reviewed the Definition Section and made other technical changes specifically the statutory language. These changes were made in order for the Board to move forward with the administrative rules and meet the agreement with JCAR. There may be other definitions in this Section that are outdated and need work also. Sean requested that the Board move forward with the changes for now and the other definitions were changed particularly the definition for facility were needed to comply with the MC/DD Act. If the Board feels that they want to review in more detail to update other definitions or to strike other definitions, this can be done over the Summer and then resubmit the Section in the second round of amendments.
2. Dr. Pyo stated that there were several changes made in the Definition Section. She indicated that the word “psychiatrics” is not really correct. There are several items regarding epilepsy and she does not think it is a correct definition and should be corrected. Mike Bibo expressed some changes are needed to be made with JCAR in order to keep commitments made in the past. Mike also expressed that Sean recognizes that there are changes to be made over the Summer. However, the Department is just asking to move these amendments forward for now to clean up everything, per JCAR.

Sean also informed the Board that changes can be made at the Public Comment period. Dr. Pyo agreed.

3. Lois Sheaffer-Kramer agreed to discuss the definition in the Summer. These amendments were reviewed by IHCA and were agreed upon and it is understood that more work is needed. Lois agreed to move the current amendments through.
4. Connie Jensen asked the Board for a motion to move the amendments as written forward with additional discussion on definitions at a later date. Lois Sheaffer-Kramer moved to carry forward and Mike Bibo seconded. Voted unanimously, motion carried.

C. Anonymous and Non-Anonymous Complaint Surveys:

1. Mike Bibo wanted a brief discussion on one of the roles for the Board. One of the Board's roles is to review the complaint survey issues whether anonymous or non-anonymous complaints. The Act states that the Department prepares a report and sends it to the Legislature by January 15th, but actually doesn't happen until July 1st. The Board had made reviews/recommendations for changes about how the material is reviewed in the past. He wanted to know how the report is broke down and noted that the Board has the role to review and make recommendations to ensure that it is being looked at clearly and specifically to DD. He feels the Department has reverted back on this process. Connie Jensen asked was there any particular reason Mike Bibo thinks the Department has reverted back. Mike Bibo indicated there was a discussion regarding this report approximately two (2) years. He indicated the Board was informed last year that it would receive the report. However, the Board never received the report. He wanted to ensure that the Board has been advised, per the Act. Darlene Harney informed him that the report is placed on the website. Subsequently, Mike Bibo advised the Board that he would like to have this as an agenda item for the next meeting and Dr. Balcazar concurred. Connie Jensen ensured it would be added to the next agenda.
2. Lois Sheaffer-Kramer inquired as to the current status on the restraint language. Are there any updates? Sean Dailey stated there was an informal agreement the Department was going to adopt the Federal rules, however, there has been a delay because of other pertinent projects.
3. Mike Bibo informed the Board that Darlene Harney is leaving the Department. He wanted to show his appreciation for her leadership and assistance and has felt as though it has been more of a partnership. He thanked her and wished her well.

VI. Next Meeting

Next Board Meeting is August 8, 2018 at 10:00 am

Agenda items to Connie Jensen, connie.jenson@illinois.gov by July 23, 2018.

Connie Jensen asked for a motion to adjourn. The motion to adjourn was made by Lois Sheaffer-Kramer, seconded by Jeff Stauter. Voted unanimously. Meeting was adjourn at 10:39 a.m.