

Special Commission on State Institutions

Meeting Minutes

January 18, 2024

3:00 - 4:30 pm

Date of meeting: Thursday, January 18, 2024

Start time: 3: 05pm

End time: 4:30 pm

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1*	Vote 2	Vote 3
Evelyn Mateo (co-chair) – Department of Mental Health (DMH)	-	-	-
Matthew Millett (co-chair) – Department of Developmental Services (DDS)	X	X	X
Elise Aronne – Wrentham Developmental Center	-	O	-
Kate Benson – DMH designee	X	X	X
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	-	X	X
Anne Fracht – DDS designee	X	X	X
Alex Green – The Arc of Massachusetts designee	X	X	X
Rania Kelly – MassFamilies	X	X	X
Andrew Levrault – Disabled Persons Protection Commission	X	Present	X
Mary Mahon McCauley – Massachusetts Office on Disability	X	X	X
Vesper Moore – Kiva Centers	X	X	-
Brenda Rankin – Wrentham Developmental Center	X	X	-
Conor Snow – Secretary of State, Archives Division	X	X	X
Mary-Louise White – DMH	-	-	-

* (X) Voted in favor; (O) Opposed; (A) Abstained from vote; (-) Absent from meeting or during vote

Proceedings

Mr. Millett, Commission Co-chair, called the meeting of the Special Commission on State Institutions to order at 3:05 pm. He reminded members that the meeting must follow the Open Meeting Law. He told Commissioners that CART services were available for the meeting. He told the group that his co-chair Evelyn Mateo would not be in attendance.

Vote 1 to approve the 10/20/2023 meeting minutes: Mr. Millett requested a motion to approve the minutes from the Commission’s previous meeting on October 20, 2023. Ms. Rania Kelly introduced the motion, which was seconded by Mr. Andrew Levrault and approved by roll-call vote (see record of votes above). Reminder that the Commission’s meeting materials are available on the Commission’s webpage.

Mr. Millett reminded the Commission that at the last meeting, The Center for Developmental Disabilities Evaluation and Research (CDDER) from UMass Chan Medical School was voted to support the work of Commission. The CDDER team, Emily Lauer, Jennifer Fuglestad, and Christine Clifford introduced themselves.

Dr. Emily Lauer presented a discussion of CDDER's support for the Commission's work.

- CDDER has created an email address for the Commission: SCSI_Support@umassmed.edu. This email is available to all on the CDDER team.
- Dr. Lauer explained that CDDER will be paid through an Interagency Service Agreement (ISA) with DDS. This is another term for a contract. The scope of the work was developed based on the Commission's ideas and is in the process of approval. Funding is available through June 30, 2024. Work is planned into the next fiscal year, which starts July 1, 2024. CDDER will work with the legislature to move remaining funding in the next fiscal year. Mr. Green confirmed that funding comes through the legislature's Ways & Means Committee and Mr. Hernandez confirmed that the discussion about funding was in process.
- Dr. Lauer offered CDDER to set up a YouTube Channel if needed. Ms. McCauley reported that her staff posted the meetings to the Office of Disability YouTube Channel. The Commission agreed that they would like CDDER to create a YouTube channel for them.
- Dr. Lauer asked whether the Commission would like CDDER to design slides for the Commission. Commissioners asked CDDER for examples. CDDER will bring samples for the Commission to review at the next meeting.
- Dr. Lauer presented the idea of making working groups under the Commission. Working groups would match the goals of the Commission:
 - Existing Records & Request Process
 - Burial Locations
 - Framework for Public Recognition

Commissioners could choose to be in these working groups. The groups would focus on areas of the Commission's work. Ms. Benson and Mr. Millett agreed setting up work groups would be a good idea. CDDER will send an email and people can sign up for which group they would like to join.

- CDDER asked the Commission how often they would like to meet. CDDER shared the idea of meeting every two months. The Commission agreed to that schedule with working group meetings in between the full Commission meetings. CDDER will send out the schedules, once work groups assignments have been completed.

Mr. Millett opened the discussion on whether or how the Commission should respond to the Boston Globe article that talked about Fernald State School and the medical records of people who lived there.

Possible responses could include letter of response to the Globe, a letter of inquiry (a letter with questions that the Commission would like to ask) to look at facts, or do nothing publicly.

- Mr. Hernandez from DDS reported that DDS contacted the City of Waltham and offered to take control of the documents. Teams have visited Fernald to start the clean-up of the papers. They entered some buildings, but some were unsafe to enter. The records are now with DDS in storage, being reviewed and sorted by DDS's privacy lawyers. Then the files can be stored correctly or destroyed if they cannot be saved.
- Mr. Clark, who was quoted in the article, said he thought the article was good and made clear that the state did not appropriately care for the records.
- Ms. McCauley stated that it was sad that the documents have been disrespected and wondered if there was an update from the Boston Globe.
- Mr. Green reported that a Globe reporter had directly contacted him. He stated that any response should come from the Commission as a whole and not individual people on the Commission. He asked what the letter of inquiry would include.
- Ms. Benson also wondered what a letter of inquiry would look like and what kind of response would the Commission submit.
- Dr. Lauer shared that a letter of inquiry could ask to gather more information, ask questions about future storages plans, or ask to figure out what went wrong with keeping these records safe, so this doesn't happen again.

Vote 2 for the Commission to form a working group to develop a letter of inquiry on the Boston Globe articles. Mr. Alex Green introduced a motion to form a working group to draft content for a letter of inquiry to look into the facts of what was shown by the Boston Globe article. Ms. Kate Benson seconded the motion.

- Commission members interested in being a part of this working group should email SCSI_Support@umassmed.edu

Next topic of discussion: Update from CDDER on the Plans and Goals of Commission
(See Power Point Slides)

Goals 1 & 2: Existing records and request process

- Dr. Lauer reported the Commission needs to define the term "institution." Institutions can mean schools like Fernald, state psychiatric hospitals, reform schools, alms houses, etc. This includes a broad range of people, not just those with intellectual or developmental disabilities (IDD).

- Ms. McCauley suggested that the focus should remain on IDD and mental health, where possible. Ms. Benson suggested that sanatoria for tuberculosis (a lung disease) and almshouses were more focused on the poor.
- Dr. Lauer reported that different types of records were held by institutions and those records are in different places. For example, private medical records of people who lived in institutions; information about who lived at these places like the date they moved, their name, age, family members, etc. These records were sometimes updated with information when people move out or death dates. Some are business records such as maps of facilities, some include burial information. Records are held at universities, state, and city archives. There are restrictions on public access for 75-80 years.
- Ms. Benson reported that some records may be held in private collections, historical societies and on eBay. Friends of the Belchertown School has some as well.
- Mr. Snow from Mass Archives reported they hold many of these records and they are subject to public records law. Medical and psychiatric records are permanently sealed and would require a court order to access. Some are accessed through an estate or if a lawyer is given access through a client.
- Mr. Green suggested that CDDER talks to historical societies (groups of people focused on the history of an area), Waltham in particular.
- The working group for this topic will define institution and provide input on commission on next steps for record review.

Goals 3 & 4 Burial Locations

(See Power Point)

- Dr. Lauer reported that there are some cemeteries located on the grounds of institutions that are still owned by the state. Not all of the graves have names on them, some have numbers or codes. Some records related to those burials have been lost. Others are buried in local parish cemeteries, again many with unmarked graves.

Goal 5: Framework for Public Recognition

(See Power Point)

- Dr. Lauer reported that there are some memorials in place or are still being made. Some cemetery restoration projects were run by former patients and families. Wrentham Developmental Center has a memorial walk. Dr. Lauer shared that these projects often take many years to do and need a lot of planning. The Commission will need to develop a plan and timeline, with more details to start the decision making.

- Ms. Benson reported that her group, Friends of Belchertown, has been working for 13 years to add a museum on site, she can share their process and what success would look like.
- Mr. Green suggested that some type of museum or memorialization would be a good idea. He said the Commission should "think big."

Work will continue each of these goals through the work groups. CDDER will send an email for people to sign up for a work group of their choosing.

Mr. Millett thanked everyone for their participation today.

Vote 3: Adjourn meeting: Ms. McCauley entered a motion to adjourn the meeting at 4:30pm, Mr. Green seconded the motion.

Meeting Materials

1. CDDER presentation