

Special Commission on State Institutions

Meeting Minutes September 12, 2024 2:30 PM - 4:30 PM

Date of meeting: Thursday, September 12, 2024

Start time: 2:31PM

End time: 4:36PM

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1*	Vote 2	Vote 3	Vote 4
Evelyn Mateo (co-chair) – Department of Mental Health (DMH)	X	X	X	X
Matthew Millett (co-chair) – Department of Developmental Services (DDS)	A	Present	X	X
Elise Aronne – Wrentham Developmental Center	-	X	-	-
Kate Benson – DMH designee	X	X	X	X
Sister Linda Bessom – Hogan Developmental Center family member	-	-	-	-
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	-	-	-	-
Anne Fracht – DDS designee	X	X	-	X
Alex Green – The Arc of Massachusetts designee	-	-	-	-
Bill Henning – Boston Center for Independent Living (BCIL)	X	X	X	X
Laurie Medeiros – MassFamilies	A	X	X	X
Andrew Levrault – Disabled Persons Protection Commission (DPPC)	X	Present	X	X
Mary Mahon McCauley – Massachusetts Office on Disability (MOD)	X	X	X	X
Vesper Moore – Kiva Centers	-	-	-	-
Brenda Rankin – Wrentham Developmental Center	X	X	-	-
Caitlin Ramos – Secretary of State, Archives Division	A	X	X	X

* (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 2:31 PM. He welcomed members and reminded them that full Commission meetings are subject to Open Meeting Law and any votes taken are conducted via rollcall. He requested that participants stay muted as they listen, use the “raise hand” feature when they want to speak, and state their name before speaking. He also reminded everyone that any questions posted in the Zoom Q&A forum would be reviewed and addressed by CDDER towards the end of the meeting and that there would be a break midway through today’s two-hour extended meeting. Ms. Mateo, Commission Co-chair, added that CART services would be available during the meeting, and the recording and minutes would be posted on the Commission's mass.gov website.

After reviewing the meeting “housekeeping” items, Mr. Millett announced the departure of Commission member, Rania Kelley, and introduced her replacement, Laurie Medeiros, who serves on the executive board of Mass Families. Ms. Medeiros introduced herself by providing some details about her lived experience and her role with Mass Families. Mr. Millett then introduced Caitlin Ramos from the Mass Archives who replaced former member, Conor Snow.

Next, Ms. Mateo introduced Dr. Emily Lauer from The Center for Developmental Disabilities Evaluation and Research (CDDER) from UMass Chan Medical School to provide a recap of what

was talked about during the last Commission meeting held in July 2024. Dr. Lauer's recap included the following:

1. The introduction of Commission member, Bill Henning, Director of Boston Center of Independent Living, and the departure of Conor Snow, representative of the Mass Archives.
2. The response by the Governor and Secretary of the Executive Office of Health and Human Services (EOHHS) to the Commission's Letter of Inquiry, which was mainly about Fernald and included the general processes on accessing records from such institutions. The Commission voted to draft a response in the Records Access Work Group requesting for more information, verifying the information contained in the letter, and providing recommendations for next steps.
3. A news article about Nazi-related vandalism found at Fernald.
4. Work group updates were also provided:
 - Records and record access: Commissioners discussed two currently proposed state bills on records access, as well as work with the Department of Mental Health to obtain access to Foxborough State Hospital records to recreate a list of people buried on the hospital grounds.
 - Burial and burial locations: Commissioners discussed the list of known burial locations of former institutional residents in Massachusetts, as well as the gap analysis of these known burial locations, which provides details about the conditions at these cemeteries.
 - Framework for public recognition: The group talked about the presentation delivered by the Willowbrook New York memorial committee and the upcoming meetings with the California State Hospital memorial project.
5. CDDER provided a brief presentation on the history and evolution of institutions for people with mental illness and developmental disabilities. This topic will be included in the draft report to Commissioners where they'll have the opportunity to provide feedback around the scope of the Commission's research.

Vote 1 to approve the 07/18/2024 meeting minutes: Mr. Millette requested a motion to approve the minutes from the Commission's last meeting on July 18, 2024. Mr. Andrew Levrault introduced the motion, which was seconded by Mr. Henning and approved by roll-call vote (see record of votes above).

Next topic of discussion: Update from Workgroups

Before the work group updates, Ms. Mateo reminded Commissioners that all work groups are looking for more members and that any Commissioner who would like to join one should email scsi_support@umassmed.edu.

- **Records and Records Access Workgroup:**

Ms. Mahon McCauley and Ms. Fuglestad gave a brief overview on the following four topics that local law students would help research for the Commission. At the end of the presentation, Commissioners were given the opportunity to provide feedback and choose which topic should be addressed first.

 1. Medical privacy laws from all 50 states that determine when and under what conditions historic patient records become accessible to the public, including researchers and family members of former institutional patients. Laws that

determine what types of records are permanently protected and kept private. Differences in access rules when records are stored in state archives, public agencies, or private collections, e.g., a university.

2. Laws or legal rulings which define death records and HIPPA-protected records, and the difference between the two. And to provide a historical perspective of how states handle death records for the general population as compared to institutional death records.
3. Current and historical Massachusetts laws that determine what happens to a deceased patient's body, including, but not limited to the claiming and burial of the body, on-site autopsies, donations to medical science, and required consent. Lastly, how private collections manage human remains and body specimens.
4. Laws that required certain patients to provide labor at the institutions with no pay or subminimum wages.

Mr. Levrault and Ms. Ramos both agreed that topic number one is most urgent. Ms. Mahon McCauley suggested topic number four, while Ms. Medeiros recommended topic number two due to a personal experience related to guardianship and patient access records.

Ms. Mahon McCauley went on to the next topic, which pertained to the five requests (see below) that the work group would like to include in the Commission's response to the Governor and EOHHS Secretary's response to the initial Letter of Inquiry about patient records found at closed institutions. Specifically, the Commission would like EOHHS to:

1. Provide more information about the thorough searches for records that were conducted at every closed DMH and DDS facility, including the discovery of any issues with record security.
 - a. Provide a timeline for when DMH and the Division of Capital Asset Management and Maintenance (DCAMM) will work together to evaluate the closed buildings at Medfield State Hospital and of any other campuses that are partially closed and might have records security issues.
2. Provide more information about how records stored in state facilities (Taunton, Worcester, Hogan and Wrentham) and state office buildings (DDS or DMH area offices or central offices) are currently being secured.
3. Allow the Commission to work with DMH and DDS to analyze barriers to records access and develop a clearer and easier process for former patients, family members, and researchers to access available records. The Commission would also like DDS' and DMH's redaction process to align with the Mass Archives.
4. Define what is and what is not considered to be a "medical record."
 - a. The workgroup would also like to understand the reason that Dever, Monson and Foxboro hospital records have not been sent to the Archives and continue to be stored at other state facilities.
5. Give the facility location of each set of institutional records and a description of completeness and incompleteness of the record holdings.

Commissioners had a few questions about the letter of inquiry and these requests. In response to these questions, it was confirmed that DMH's, DDSs, and EOHHS's legal

departments were involved in crafting their response to the Commission's letter of inquiry and that, if the Commission decided to right a follow-up response to EOHHS, that it would include the five requests above, which would provide greater details to the Commission.

Vote 2: Send a second letter to EOHHS with the five requests: Ms. Mahon McCauley requested a motion to have the Commission send a second letter to EOHHS with the five requests stated above. Ms. Benson introduced the motion, which was seconded by Mr. Henning and approved by roll-call vote (see record of votes above).

▪ **Burials and Burial Locations Workgroup:**

Ms. Kate Benson provided the following updates on this workgroup:

- The Foxborough State Hospital cemetery records project is making progress. An agreement has been made where DMH has given CDDER permission to access the Foxborough records stored at Taunton in an effort to determine the names of the people buried at Foxborough.
 - Dr. Lauer from CDDER commended DMH for its cooperation and support with this project. She also stated that project has helped the Commission understand the differences between public and private records.
- CDDER has been researching past and present institutional burial practices, which will be included in its draft report to the Commission. A summary of this section of the report was presented at a later time during this meeting.
- There is a Memorandum of Understanding (MOU) between the Department of Public Health and Tewksbury Hospital allowing the Pines cemetery at Tewksbury State Hospital to be used as a public access way for passive recreation. An amendment to the MOU declared the cemetery to be an official part of the Bay Circuits Alliance park system. Currently, the cemetery has walking trails built over cemetery gravestones and minimal signage indicating that this was a resting place for former Tewksbury Hospital patients.
 - The Commission would like to learn more about this agreement before deciding to act. CDDER committed to distributing the MOU, including the amendment, to Commissioners shortly after the meeting. Lastly, Ms. Medeiros suggested partnering with the town's disability commission once the Commission decides to act upon this issue.

▪ **Framework for Remembrance Workgroup:**

Ms. Jennifer Fuglestad from CDDER provided the following updates on this workgroup:

- The California Memorial Project delivered a presentation to the workgroup on August 8, 2024. They discussed the process of establishing a statewide annual Remembrance Day (on the third Monday of every September since 2002) for people with mental health and developmental disabilities who lived and died in California state institutions. This included fundraising, applying for grants, and pushing for legislation (Senate Bill 1448) to formalize and partially fund this project, which was led by a team of representatives from different state agencies and disability groups. Currently, the memorial project is collecting stories from people who have lived at these institutions at any point in time, and are sharing them on their website. Some

of the major challenges that were highlighted included local community involvement and the sustainability of the project with little staffing (currently, only two people manage the entire state initiative).

- On September 25, 2024, the workgroup is scheduled to meet with Pat Deegan from the Danvers State Memorial Committee to discuss her work, with the support of DMH, to improve the cemetery conditions at Danvers State Hospital, as well as to create a memorial in the cemetery.

Ms. Mateo introduced a five-minute break before the presentation on the draft report on burials and burial locations.

Next topic of discussion: Presentation on the Draft Report on Burials and Burial Locations by CDDER

As part of the Commission's scope of research, CDDER delivered a short presentation on the following topics related to institutional burial practices and burial locations in Massachusetts. Before today's meeting, CDDER sent to Commissioners a draft copy of this section of the report along with a list of cemeteries associated with DDS and DMH state institutions and a document containing cemetery profiles. Commissioners had the opportunity to ask questions throughout the presentation.

- Burial of the Poor
 - In the 1850's, state almshouses provided food and shelter to poor people who did not have any family or a legal residence. A large portion of these people had disabilities. People who died at a state almshouse and did not have anyone to pay for their burial, were often buried on the grounds of the almshouse or in a special section of the local town cemetery. Some graves were marked with numbers on a metal marker and people were often wrapped in a robe and buried without a coffin.
- Burial of People Living in Institutions
 - Institutions provided on-site religious services through a chaplain. Chaplains would often deliver end-of-life services for the sick and dying and conduct onsite burials for inmates. Coffins and burial clothing used in burials were often produced by inmates that participated in industrial workshops. Like the almshouses, graves would often consist of a small stone slab with a number or letter representing the person's religion. Minimal grave markings were used due to the stigma around disabilities at the time. Notification to families about the death of a relative was inconsistent across institutions.
- Deceased Inmates
 - Families who could afford a burial could claim the body and make burial arrangements for their relative, while burials for unclaimed bodies would be managed by the institution and often take place somewhere within the grounds of the institution. In 1931, a bill was introduced to address the financial barrier for families to be able to bury their relatives, but it is not clear if it ever passed.
 - In the early 1800's, medical professionals wanted to advance medical science through the examination of dead bodies, but they did not have easy access to a supply of dead bodies. This led to illegal grave robbing and the selling of dead

bodies to medical schools. In 1831, a law passed that allowed institutions to give unclaimed dead bodies to medical schools for research, and, in 1931, the Promotion of Anatomical Science law made this a requirement so long as both the institution and medical school gave an opportunity for relatives to claim the body and the medical school made a formal promise to use the body strictly for medical use.

- CDDER clarified that for the above to happen, consent by people living at these institutions or assent for those with a guardian would be required.
- Institutions often had pathology departments that would perform autopsies on dead bodies to collect data around deaths, including causes of death. Consent given by family members to conduct these types of examinations was also a requirement. Institutions would also often have on-site morgues where bodies were prepared for burial.
- Funding of Burials
 - In the 1850's, laws required transportation companies to report and pay a fee to the State for any passengers that were sick and disabled. Failure to do so would result in a fine and any state-funded services, including burials, that the passenger ended up receiving would have to be paid back to the State by these companies.
 - CDDER to confirm if this applied to domestic and international travelers.
 - Burials would also be paid for by a person's town or city of legal residence or by their family, if they could afford it. If none of these were options, then the institution would cover the burial costs upfront and the State would reimburse them a certain amount of money depending on the deceased person's age.
- Death Record Laws
 - In the mid 1800's, Massachusetts required every city and town to store original birth, marriage, and death records and to make and submit certified copies of these records annually to the state. The public records laws also explained what needed to be on a death certificate, set the fees for burial and removal permits, and established a penalty for anyone who buried a body without the required permits.
 - The public records law applied to the State Almshouses differently. Instead of the town clerk, it was the institution's superintendent who was responsible for providing a copy of birth and death certificates to the state every year.
 - Death records before 1841 were kept at the town/city level; between 1841 and 1910, at both the town/city and state levels; after 1910, at the town/city level and at the Registry of Vital Records and Statistics.
 - Ms. Ramos made a correction and stated that the State Archives has state copies of birth, marriage, and death records from 1841 through 1930 and that the Registry of Vital Records has copies of state records from 1931 to present day. Lastly, the Registry of Vital Records sends copies of state records to the State Archives in five-year intervals.
- Cemeteries
 - The typhoid fever epidemic in the late 1800's and the Spanish Flu pandemic of 1918 led to many deaths, which impacted where inmates were ultimately buried. For

example, institutions could no longer rely on local cemeteries for burials and had to build cemeteries on the grounds of the institution.

- As of now, the Commission has identified a total of 27 institutional and town cemeteries where deceased inmates have been buried.
 - According to Pat Deegan's research in the 1990's, there are roughly ten thousand DMH patients that are buried across the state. More work needs to be done to determine an estimate of DDS patients that have been buried across the state.
- Cemetery profiles, which are based on the gap analysis that the burials work group developed, include information about the different names a cemetery is known by, its location, the type of cemetery it is (institutional vs. town cemetery), estimate of how many people are buried there, vandalism, memorials, etc.
 - A profile on Pine Hill cemetery located in Tewksbury will be included as this is the cemetery where authorized medical schools bury bodies that are donated to medical research.
- Areas for Additional Research
 - The Commission decided to have this part of the presentation delivered during the Commission's next meeting scheduled on October 17, 2024.

Vote 3: Create a Workgroup to Review Commission Reports: Ms. Benson requested a motion to create a separate work group to help edit reports from each work group, including the Burials and Burial Locations, the Records and Records Access, and the Framework for Remembrance workgroups, as well as the Commission's final report due in January 2025. Mr. Levrault introduced the motion, which was seconded by Ms. Medeiros and approved by roll-call vote (see record of votes above).

Vote 4: Adjourn meeting: Ms. Mateo reminded everyone about the next full Commission meeting scheduled for October 17th, 2024, from 2:30PM to 4:30PM. Thereafter, Ms. Medeiros entered a motion to adjourn the meeting at 4:36PM, Ms. Mahon McCauley seconded the motion (see records of votes above).

Meeting Materials

1. SCSJ meeting presentation
2. SCSJ meeting minutes from September 12, 2024
3. Analysis of response to the Letter of Inquiry
4. Plain language summary of Best Interest Determination Memo from DMH
5. Law clinic scenarios regarding records and records access
6. Draft report on burials and burial locations
7. List of town and institutional cemeteries
8. Cemetery profile samples