

Special Commission on State Institutions

Meeting Minutes

May 30, 2024

3:00 - 4:30 pm

Date of meeting: Thursday, May 30, 2024

Start time: 3:03pm

End time: 4:08pm

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1*	Vote 2
Evelyn Mateo (co-chair) – Department of Mental Health (DMH)	X	X
Matthew Millett (co-chair) – Department of Developmental Services (DDS)	X	X
Elise Aronne – Wrentham Developmental Center	-	-
Kate Benson – DMH designee	X	X
Sister Linda Bessom – Hogan Developmental Center family member	X	X
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	X	X
Anne Fracht – DDS designee	X	X
Alex Green – The Arc of Massachusetts designee	-	-
Rania Kelly – MassFamilies	X	-
Andrew Levrault – Disabled Persons Protection Commission (DPPC)	X	X
Mary Mahon McCauley – Massachusetts Office on Disability (MOD)	A	X
Vesper Moore – Kiva Centers	X	X
Brenda Rankin – Wrentham Developmental Center	X	X
Conor Snow – Secretary of State, Archives Division	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 3:03 pm. He welcomed members and reminded them that full Commission meetings are subject to Open Meeting Law and any votes taken are conducted via roll-call. Ms. Mateo, Commission Co-chair, also informed Commissioners that CART services would be available and meeting notes would be taken during the meeting, and that the meeting would be recorded and made available on the Commissioner's mass.gov page and YouTube channel.

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 March 2024. Dr. Lauer's recap included the following:

1. New commission member, Sister Linda Bessom, was introduced, along with Julia O'Leary from the MOD who was representing Mary Mahon McCauley in her absence.

2. CDDER presented a few PowerPoint template examples to the Commission, and they chose the template that was used during this meeting.
3. CDDER informed members about the YouTube channel they created for the commission and that all past videos were moved there.
4. Commissioners discussed recent news articles from the Boston Globe, developments at Bridgewater State Hospital, Tewksbury State Hospital and Fernald State School.
 - The discussion about Fernald included things like the worsening conditions of the buildings, records that were left behind, a privacy breach notice issued by DDS in response to the records that were found, and commissioners expressing they want former patients and their family members to decide what happens to the grounds of these closed institutions.
5. Commissioners talked about what types of institutions would be included in its research.
6. Workgroup updates were also provided:
 - Letter of inquiry: Commissioners reviewed and approved the draft letter of inquiry that asked Governor Healey and the Secretary of Health about finding records that may still be located at closed institutions, to resolve security issues at these locations, and make the process to request records easier for former patients and family members.
 - Records and record access: The group shared what they learned about record retention guidelines, which is how long records need to be kept, the record access process, and next steps.
 - Burial and burial locations: The group shared what they learned about the status of cemeteries, including where they are located and whether they're being taken care of or not. A gap analysis of existing cemeteries was also discussed.
 - Framework for public recognition: The group talked about the vision, mission, and goal of the remembrance, as well as what they learned from other states who have remembered people who lived in these types of institutions.

Vote 1 to approve the 03/21/2024 meeting minutes: Mr. Millett requested a motion to approve the minutes from the Commission's last meeting on March 21, 2024. Mr. Andrew Levrault introduced the motion, which was seconded by Ms. Anne Fracht 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

Next topic of discussion: Commonly Used Terms and Acronyms

Ms. Mateo talked about the reference tool that CDDER sent to members for review in April, which they developed to help clearly communicate complex information to members. She informed members that the document would be updated as needed and is available for anyone who would like to use it.

Next topic of discussion: Timeline for SCSI Work – Next Steps and Meetings

Dr. Lauer reviewed a proposed timeline for the Commission's work. Currently, the Commission is in the process of research and information gathering. Next steps include CDDER drafting and submitting a report to Commissioners for review by September 30, 2024. Members can follow up with CDDER with questions and feedback as needed. CDDER will send a final report to the Commission by January 15,

2025. The Commission will use this report to decide on the design of the framework for remembrance and any other recommendations for next steps to the legislature.

Dr. Lauer also reminded members that the next full Commission meetings are scheduled for July, September, and November. She then asked the group if they would like to schedule any additional two-hour meetings before the January due date to give the Commission enough time to read the report individually and discuss it as a group. Most members agreed and CDDER committed to sending members some potential dates for these additional meetings.

Next topic of discussion: Recent Developments

Mr. Millett discussed the following news articles that have been published since the last full Commission meeting:

- One WGBH article reported concerns from community members regarding the lack of input from the community and former patients from the city of Waltham about the plans for development of the Fernald grounds.
 - Mr. Reggie Clark, Commissioner, was interviewed for this article and told the reporter that the mayor of Waltham should collect and include input from former residents like himself before making any decisions about what to do with Fernald. He also suggested having someone from the legislature investigate and ensure that the mayor fulfills the desires and wishes of former residents who provide input for this project.
- Another WGBH article provided an update about a family member of a former patient who asked Governor Healey for help in accessing his brother's records from Fernald.
 - Mr. Reggie Clark, Commissioner, supported this individual's efforts to get access to their brother's records and expressed that he feels strongly that people should have easy access to what belongs to them.
- The Boston Globe wrote an article about confidential files from the Massachusetts State Police that were found unsecure in the buildings at Fernald.
 - Ms. Mary Mahon McCauley was saddened by this news but also glad that it was disclosed to the public. She hopes the State Police and any other state agency involved take corrective and preventive action, so this does not happen again.
 - An unknown meeting participant asked whether these records were removed, and Deputy Assistant Commissioner, Victor Hernandez, stated he believes that they were, but suggested they reference the article to get confirmation to their question.
- The Worcester Telegram and Gazette wrote an article about a citizen searching for unmarked graves on the grounds of the former Westboro State Hospital/Lyman Reform School for Boys.
 - Mr. Millet added that this article did include a quote that was drafted by CDDER and approved by him and his fellow co-chair, Ms. Mateo. The quote expressed the need to follow all state laws and local by-laws when searching for these types of sites.

Next topic of discussion: Update from Workgroups

Ms. Mateo stated that the workgroups are still looking for additional members and that Commissioners can sign up to any workgroup by emailing the SCSJ Support email address. Next, Mr. Millet invited each workgroup to provide an update.

- **Workgroup 1: Letter of Inquiry**

Mr. Clark provided the following update on this workgroup:

- The Commission is still waiting for a response to the letter of inquiry that was emailed on March 27, 2024. The Commission requested that the Governor and the Secretary of Health provide a response to the letter by June 25th, 2024. The response will be shared with members once it is received.

- **Workgroup 2: Records and Record Access**

Ms. Mahon McCauley provided the following updates on this workgroup:

- Many years ago, there was a state bill that was proposed to give people access to public records from institutions after 75 years. The bill never passed.
 - Mr. Levrault asked if the proposed bill was specific to the access of public records by the Commission, but it was confirmed by Dr. Lauer that the most recent proposed bill, which did not pass, was to benefit the public. Dr. Lauer also stated she believed that the Commission's authority to request records is unchanged.
- Through its research findings, the workgroup is concerned about items containing personal information from former state schools being sold on sites like eBay. To get access to these records, the workgroup is considering having an amnesty program where people who have these personal records can turn them in without facing any legal charges.
- The family member who was interviewed by WGBH about requesting his brother's records from Fernald during an Ask *the Governor* event, finally received the records.
- CDDER has received record access guidelines from 36 states. The workgroup will examine this information and take it into account when making recommendations on how to make the record access process easier in Massachusetts.

- **Workgroup 3: Burial and Burial Locations**

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

- The gap analysis tool to evaluate institutional cemeteries has been completed. The group is considering best practices for carrying out these evaluations.
- The workgroup is in the process of compiling a list of known burial locations of former residents of institutions. The group understands that former residents of certain institutions might be buried in non-institutional cemeteries.
 - An unknown meeting participant asked about creating a database of identified people buried in these institutional cemeteries.
 - Dr. Lauer stated that there are community groups that have started database work that the Commission could benefit from, and the database idea could be a recommendation in the Commission's final report.
 - Mr. Vesper Moore suggested referencing resources like the Carlyle Industrial School in Pennsylvania that have created similar databases.

- Current burial practices have been collected from Hogan Regional Center and Wrentham Developmental Center, which are still open.
 - The workgroup has learned that there is a need to educate local towns and city officials about how to properly search for unmarked graves. This can be done through the development of educational materials by the Commission or by having the Commission make the recommendation for educational materials to be developed within their final report.
 - Sister Linda Bessom expressed that she supports the first idea and that it would be beneficial to have the materials reviewed by outside consultants.
- **Workgroup 4: Framework for Public Recognition**

Ms. Rania Kelly provided the following updates on this workgroup:

- Since the last Commission meeting, the workgroup learned about the work of the Friends of Belchertown State School Association on how to create a disability history museum.
- The work group is scheduled to interview Tewksbury State Hospital Museum of Public Health about its memorial for former residents.

Ms. Jennifer Fuglestad provided the following update on this workgroup:

- All Commissioners are invited to attend a presentation by the Willowbrook Mile steering committee chair, Diane Buglioli, scheduled for June 7, 2024. The presentation will be about the 10-to-15-year process that it took the steering committee to develop the Willowbrook mile memorial on the grounds of the former institution on Staten Island.

Ms. Mateo thanked everyone for their participation today. She also reminded everyone that the next Commission meeting will take place on Thursday, July 18th at 3:00PM. She also notified Commissioners that they will soon be sending out the meeting schedule for the rest of the year.

Sister Linda Bessom asked if the Commission could create a list of the different workgroups, including its members and contact person, in the event anyone wants to join a workgroup. Mr. Millet suggested that if any Commissioners have any questions about the workgroups, that they email the SCSI Support email address.

Vote 2: Adjourn meeting: Mr. Clark entered a motion to adjourn the meeting at 4:08pm, Ms. Mahon McCauley seconded the motion.

Meeting Materials

1. SCSI presentation