

## Special Commission on State Institutions

### Meeting Minutes

January 23, 2025

3:00 PM - 5:00 PM

Meeting date: Thursday, January 23, 2025

Start time: 3:00PM

End time: 4:57PM

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1	Vote 2	Vote 3	Vote 4	Vote 5
Alex Green – The Arc of Massachusetts, designee	X	X	X	X	X
Andrew Levrault – Disabled Persons Protection Commission (DPPC)	X	X	X	X	X
Anne Fracht – Department of Developmental Services (DDS), designee	X	X	X	X	-
Bill Henning – Boston Center for Independent Living (BCIL)	A	X	X	X	X
Brenda Rankin – Wrentham Developmental Center	-	-	-	-	-
Elise Aronne – Wrentham Developmental Center	-	-	-	-	-
Evelyn Mateo – Department of Mental Health (DMH)	A	X	X	X	X
James Cooney – Department of Mental Health (DMH)	X	X	X	X	X
Kate Benson – (co-chair) DMH, designee	X	X	X	X	X
Laurie Medeiros – MassFamilies	X	X	X	X	X
Mary Mahon McCauley – Massachusetts Office on Disability (MOD)	X	X	X	O	X
Matthew Millett (co-chair) – DDS	-	-	-	-	-
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	-	X	X	-	-
Samuel Edwards – Secretary of State, Archives Division	X	X	X	O	X
Sister Linda Bessom – Hogan Developmental Center, family member	-	-	-	-	-
Vesper Moore – Kiva Centers	X	X	X	X	X

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

**Proceedings:** Ms. Benson, Commission Co-chair, called the meeting of the Special Commission on State Institutions to order at 3:00 PM. She welcomed members and reminded them that full Commission meetings are subject to Open Meeting Law and any votes taken are conducted via roll call. She requested that participants stay muted as they listen, use the “raise hand” feature when they want to speak, and state their name before speaking. She also stated that questions would be addressed during question-and-answer periods and that there would be a break midway around 4:00PM. Ms. Benson also 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.

**Next Topic:** Recap of 12/12/2024 Commission Meeting

After reviewing the meeting “housekeeping” items, Ms. Benson 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 on December 12<sup>th</sup>, 2024. Dr. Lauer’s recap included the following:

**Commission General Updates:**

1. The Commission voted and appointed Mr. Alex Green as secretary of the Commission. The vice chair position has not been filled.
2. The Commission agreed to continue meeting monthly in 2025 to talk about the findings from the CDDER report and put together recommendations due by June 2025.
3. The Report Working Group was able to get another volunteer to join.
4. Commissioner, Mary Mahon McCauley, announced her upcoming retirement and that someone from the Massachusetts Office on Disability would be replacing her.

**Summary of Draft Report Continued:** CDDER shared the rest of its findings on key focus areas from its report. The discussion covered examples of patient records from institutions over time, Massachusetts public records laws, and how to request these records. They also talked about who can access patient records, how long they must be kept, and the types of records available at the Massachusetts State Archives. Additionally, they discussed experiences with private collections and obtaining information on deceased family members. Finally, they discussed lessons learned from groups from other states that have created memorials for people who lived in institutions.

**Vote 1:** Ms. Benson requested a motion to approve the minutes from the Commission’s last meeting on December 12, 2024. Ms. Laurie Medeiros introduced the motion, which was seconded by Mr. Andrew Levrault and approved by roll-call vote (see record of votes above).

---

**Next Topic:** Upcoming Work of Special Commission

**SCSI Recommendations & Report:** Ms. Benson expressed the need for the Commission to make a plan on reviewing CDDER’s final report, including questions about the report, deciding how to create recommendations based off said report, and writing the SCSI report, which will contain the Commission’s recommendations and is due to the legislature by June 1, 2025. She provided an example of discussing one topic per meeting and coming up with related recommendations.

**Discussion:**

1. Ms. Lauri Medeiros was wondering if there were four main topics to discuss since the Commission would meet four times before the final SCSI report due date.
  - a. Dr. Emily Lauer from CDDER clarified that the CDDER report has three main topics, including burials, records, and a framework for remembrance, and that the Commission can choose how to structure these discussions. She stated the Commission might want to cover each of the three areas and have a final meeting to agree on recommendations. And, if needed, the Commission could have multiple meetings on one topic.
  - b. Mr. Alex Green added that now that the Commission has the CDDER report it is the Commission’s task to write a summary reflecting the Commission’s opinions and what Commissioners want to communicate to the legislature or the public. He also stated that the Commission has created a subcommittee to draft this summary based on discussions, aiming to summarize the report into a few pages with the key takeaways and recommendations made by the Commission.

2. Ms. Medeiros asked a follow-up question about whether the Report Working Group will be writing the recommendations or if the whole Commission will discuss the topics monthly, with the working group then meeting separately to gather information.
  - a. Mr. Green explained that both were possible and that the working group has experts, like an official from the archives, who can provide detailed information. However, he stressed that it's crucial for all Commissioners to share their thoughts during group meetings since everyone will vote on the final recommendations, so everyone is happy with the final summary and recommendations.
  - b. Ms. Benson agreed with Mr. Green, suggesting that discussing each topic individually in the big group would ensure everyone's voice is heard. She emphasized that the Report Working Group is open to anyone and they welcome input from everyone.
3. Mr. Bill Henning recognized the hard work put into CDDER's final report. He also provided feedback to add in the executive summary of the report the Americans with Disabilities Act (ADA) and how it led and related to Olmstead.
  - a. Dr. Lauer mentioned that the report is marked "not for distribution," and that CDDER can make these adjustments if the Commission decides to share it publicly.
4. Before moving on to the next topic, the group discussed whether to vote on the approach at this time or to wait until the end of today's meeting. Dr. Lauer suggested they could decide later after reviewing the potential areas of opportunity for recommendations, ensuring everyone has a chance to weigh in before adjourning.

---

**Next Topic:** 2025 Upcoming Meeting Schedule

**Schedule Options:** Ms. Benson discussed the meeting schedule from February to June 2025, proposing two options: meeting on the second (02/13/25; 03/13/25; 04/10/25; 05/08/25) or the fourth Thursday (02/27/25; 03/27/25; 04/24/25; 05/22/25) of every month, both from 3:00 to 5:00 PM. She asked for preferences on these options and highlighted that the first option allows for more time between the Commission meeting in May and the June 1<sup>st</sup> SCSJ report deadline.

**Discussion:**

1. Mr. Samuel Edwards asked why Thursday was chosen as the meeting day.
  - a. Ms. Benson explained that Thursday was the day that was selected the most in the scheduling polls that CDDER distributed.

**Vote 2:** Ms. Benson requested a motion to approve option 1, which includes the Commission meeting every second Thursday of the month from February through May 2025. Mr. James Cooney introduced the motion, which was seconded by Mr. Vesper Moore and approved by roll-call vote (see record of votes above).

---

**Next Topic:** CDDER's Report

Dr. Emily Lauer stated that the CDDER report was sent to Commissioners on January 15<sup>th</sup>, 2025. She reminded them that the report uses historical language that may be offensive today but reflects past attitudes towards people with disabilities. She briefly went over the report's main topic areas, overall structure, and opportunities for consideration. Feedback and questions were encouraged during the discussion or via email.

**Main Topics:**

- Historical Timeline: Explores Massachusetts' history of care for people with disabilities and other groups, showing changes in support over time.
- Records and Records Access: Discusses the creation, storage, and access issues of old institutional records, including privacy rules and access difficulties.
- Burials and Burial Locations: Covers laws, regulations, and records related to burials, the condition of cemeteries, unmarked graves, and identification of buried individuals.
- Framework for Remembrance: Describes the methods used by Massachusetts and other states to remember and honor those buried, based on lessons learned over the past year.

**Report Structure:**

- Executive Summary: Provides a quick overview of the report's main points, including opportunities for consideration. A plain language version of the executive summary is available. Mr. Alex Green also produced an audio recording of the plain language executive summary for Commissioners to listen to, if they prefer.
- Attachments: Ten additional documents provide more details and information, referenced within the larger report. These have been shared with the Commission over the past year.

**Discussion:**

1. Mr. Edwards thanked the CDDER team for their hard work, appreciated the historical overview and information on record locations, and mentioned he would email to clarify some inaccuracies about the Massachusetts State Archives.
2. Ms. Medeiros expressed admiration for the impressive and comprehensive report, praising the dedication of its creators and feeling honored to read their work.
3. Dr. Lauer expressed gratitude for the positive feedback from Commissioners, emphasized the report's value for reference and education, and invited further comments or contact with CDDER.

---

**Next Topic:** Presentation of Potential Areas of Opportunity for Recommendations by CDDER

**Potential Areas of Opportunity for Records and Records Access:**

- Rules Governing Records Access: The first opportunity is to suggest changes to laws so families can access institutional records more easily and clearly, and to clarify if state agencies can confirm record availability before families need to go to court or pay fees. Another opportunity is to set a specific time period before individual records from state institutions can be accessed at the Massachusetts State Archives, as there is no current Massachusetts law for this. It is also recommended to update the Statewide Records Retention Schedule to keep these records safe once they are no longer needed by agencies, noting that medical records are currently kept for 20 years before they can be destroyed.
- Record Locations: The Commission could ask for a detailed list of institutional records held by DDS and DMH, suggest rules for managing records when an institution or office closes, and request information on any records DDS and DMH sought to destroy in the past.
- Privacy Laws in Relation to Records: Another idea is to ask the Supervisor of Records how Massachusetts privacy laws should be understood, especially since other states interpret HIPAA (Health Insurance Portability and Accountability Act) differently. Recent legal arguments

suggest changes to public record laws might affect the protection of medical records, so the state needs to balance public access with privacy.

- Access to Private Collections: The Commission could suggest ways to access private collections with information about former patients at state institutions, which may not be covered by state retention laws.
- Create a Pathway for the Public to Return Records: When state hospitals and schools closed from the 1970s to early 2000s, private patient records were left behind and found by "urban explorers," with some items taken or sold online. The Commission could recommend a way to return these stolen items to the state for protection and preservation.

### **Discussion:**

1. Ms. Medeiros questioned whose privacy is being protected when an individual has passed away and suggested looking into whether individuals with disabilities or family members serve on the Records Conservation Board, as their biases could influence existing policy on public records. She also emphasized the need for reasonable timelines for families to access records of deceased loved ones, questioning the fairness of waiting until they are very old to access these records.
  - a. Mr. Green agreed with Ms. Medeiros point about including diverse board members and emphasized the importance of considering different perspectives on how long medical records should be kept before being accessible. He mentioned that the CDDER report provides examples of laws from other states and suggested that the group think about what is fair and reasonable for both families and researchers in Massachusetts. Mr. Green also highlighted that many people who died in institutions did not have children, making it difficult for other relatives to access their records. He questioned whether current practices protect the state more than the individuals or public interest, suggesting that this issue needs to be addressed in the Commission's final report.
  - b. Mr. Edwards mentioned that Massachusetts has specific laws for medical and developmental disability records that need adjustments. He suggested considering sunset laws that make records public after a set period of time and highlighted the challenges families face in accessing records. He also noted that many requests come from both families and researchers, and that the Massachusetts State Archives are working on tracking these requests more accurately.
  - c. Dr. Lauer explained that the privacy law in Massachusetts was designed to help people seek mental health treatment without fear that their family members would find out, even after their death. She emphasized the importance for Commissioners to understand this piece of history to appreciate the law's intention and its impact on encouraging people to seek necessary mental health services.

**\*\* FIVE-MINUTE BREAK (4:04PM – 4:09PM) \*\***

### **Potential Areas of Opportunity for Burials and Burial Locations:**

- Repealing Chapter 113: It was explained that Chapter 113 allows state institutions to send unclaimed bodies to medical schools, but this practice is now uncommon as medical schools use anatomical gift programs. The Commission could consider repealing this outdated law.

- Unmarked Graves: Unmarked graves at old town cemeteries or state institutions are hard to find and protect, often due to missing or moved grave markers. The Commission could create educational materials for local officials and urban planners on handling unmarked graves and recommend further research, including funding and land surveys, to locate these graves.
- Cemetery Preservation and Restoration: Cemetery preservation and restoration is important, with many institutional cemeteries needing evaluation and repair. This includes assessing structures like stone walls, creating accurate burial inventories, and addressing issues like erosion and overgrowth. An example is the MetFern Cemetery, which received Community Preservation Act funding for restoration in 2019, but the funds were returned as they were not used. The Commission can make recommendations based on these overall findings.
  - Cemeteries known to need restoration and/or preservation include: the Potter's Field at Mt. Hope Cemetery, which is associated with Boston State Hospital; Bridgewater State Hospital's two cemeteries, the State Farm Cemetery and the Morgue Cemetery; Foxborough State Hospital's two cemeteries, the State Hospital Cemetery and the Rock Hill Cemetery; Metropolitan State Hospital and the Fernald burial site known as MetFern Cemetery; Northampton State Hospital's Hospital Cemetery (also called Hillside Cemetery); Tewksbury Hospital's two cemeteries, the Pines and the Livingston Street Cemetery (No-Name Cemetery); Worcester State Hospital's Hillside Cemetery.
  - Cemeteries to evaluate for restoration and preservation include the State Hospital Cemetery that was used by Gardner State Hospital and the East Gardner Colony; the Grafton State Hospital Cemetery and Hillcrest Cemetery; Taunton State Hospital's Mayflower Hill Cemetery; Templeton Developmental Center's Pine Grove Cemetery; and Worcester's State Hospital's Hope Cemetery.
- Identify People: The Commission could recommend making public the lists of people buried in cemeteries where only numbers were used to identify graves. This includes cemeteries at Boston State Hospital, Bridgewater State Hospital, Foxborough State Hospital, Gardner State Hospital, Metropolitan State Hospital, Northampton State Hospital, Taunton State Hospital, Tewksbury State Hospital, Worcester State Hospital, and Fernald State School.
- Install Signs: Many state hospital cemeteries lack proper signs, making them hard to recognize and care for. The Commission could recommend adding signs and memorials to explain the hospital's history and honor the people buried there, including at Boston State Hospital's Mt. Hope Cemetery, Bridgewater State Hospital's State Farm Cemetery, Foxborough State Hospital's Rock Hill Cemetery, Grafton State Hospital, MetFern Cemetery, Northampton State Hospital burial grounds, Taunton State Hospital's Mayflower Hill Cemetery, Tewksbury State Hospital's The Pines and No-Name Cemetery, and Worcester State Hospital's Hillcrest East and Hope Cemetery.
- Address Conditions at "The Pines" in Tewksbury: The Pines Cemetery in Tewksbury is historically significant but faces challenges like hiking trails that disturb gravesites and deteriorating grave markers. Local volunteers maintain the cemetery, but its size and age make consistent care difficult, and there are not enough resources for sustainable preservation. Recommendations the Commission could make include coming up with a plan to improve and protect the cemetery, including rerouting hiking trails, repairing and stabilizing grave markers, and installing safety and educational signs to protect and honor the burial site.

- Close Pathway to Possibly Move Graves at Glavin Center: The town of Shrewsbury sought assistance from the Central Massachusetts Regional Planning Commission (CMRPC) to explore development options for the old Glavin Center site. One idea involves potentially moving the Hillside West Cemetery to allow for more housing or sports fields. The Commission should consider making recommendations on this as moving graves would have historical implications on the people who died while living at this institution.

#### **Discussion:**

1. In the Zoom chat, Ms. Medeiros expressed her agreement with the recommendation on eliminating Chapter 113 since it's not being used anymore.
2. Ms. Medeiros also asked who has the authority to relocate the burial ground at the old Glavin Center. She proposed that if this issue is discussed in a city or subcommittee meeting, it is important for everyone, not just descendants or relatives, to have the opportunity to voice their opinions. She believes that a collective effort from the Commission at city meetings could greatly influence the decision.
  - a. Dr. Lauer acknowledged Ms. Medeiros' question and noted that there is an opportunity to influence the decision. She mentioned that the recommendation to move the burial ground was surprising due to the challenges involved and suggested that broader input from stakeholders and residents would be beneficial. She also pointed out that Shrewsbury would need to approve any development plans, and there would be opportunities for family members and others to provide input during town meetings.
3. Mr. Green asked a question about who the Commission should make recommendations to around burials and bodies of deceased people.
  - a. Dr. Lauer explained that local boards of health, influenced by the State Board of Mental Health and burial laws, would handle these matters, including procedures for addressing unmarked graves. She noted that state boards' knowledge about these rare situations can vary, suggesting the Commission could provide more consistent information and recommendations to ensure proper practices and maintenance.
4. Mr. Green also asked CDDER, based on its research, for an estimate of unmarked graves associated with state hospitals and state schools.
  - a. Dr. Lauer mentioned that there are confirmed cases of unmarked graves and some unverified information, suggesting more may exist. She emphasized the need for further work with the State Archivist to gather historical evidence and determine which claims are credible. This process might involve forming a new commission to decide how to proceed. She noted that the CDDER report contains more details, but they lacked the time and resources to explore the issue thoroughly.
5. Mr. Cooney asked a question about the status of the Glavin Center?
  - a. CDDER has reached out to CMRPC but has yet to get a response.
6. Mr. Reggie Clark added towards the end of the meeting, but with respect to this topic, that some of these recommendations around burial and burial locations could be costly.

---

#### **Next Topic:** Commission Meeting & Report Working Group Meeting Structures

At this time, Ms. Benson circled back and continued the conversation about how the Commission would like to proceed on structuring future Commission meetings and bringing the feedback from

said meetings to the Report Working Group. Ms. Benson also reminded Commissioners to feel free to join the Report Working Group.

**Vote 3:** Consequently, Ms. Benson requested a motion to continue to discuss the CDDER report in these three sections as a large group in the full monthly Commission meetings, to then bring the information into the smaller Report Working Group. Ms. Laurie Medieros introduced the motion, which was seconded by Mr. Green and approved by roll-call vote (see record of votes above).

---

**Next Topic:** Possible Release of CDDER's Report

Before adjourning, Mr. Green raised the topic of whether the Commission thinks it would be appropriate to publicly release CDDER's report. In response to this, Ms. Medeiros raised the fact that some Commissioners during today's meeting pointed out some minor edits that should be made to the report. Dr. Lauer suggested making a motion to release the CDDER report once Commissioners have had a chance to review and share their feedback with CDDER, which CDDER will incorporate in the report.

**Vote 4:** Ms. Benson requested a motion to release the CDDER report to the public once all feedback has been collected and report modifications have been made. Mr. Andrew Levrault introduced the motion, which was seconded by Ms. Anne Fracht and approved by roll-call vote (see record of votes above).

---

**Next Topic:** Additional Questions and Comments

**Discussion:** Ms. Medeiros suggested organizing the next three full Commission meetings by starting with quicker topics and saving the more complex ones like the cemetery recommendations for last, which would allow for extra time for discussion. Ms. Benson agreed, also noting that having a clear agenda for each meeting will help ensure thorough discussions, especially regarding the lengthy burial topic.

---

**Next Topic:** Adjourn Meeting

**Vote 5:** Ms. Benson asked if there was a motion to adjourn. Mr. Green introduced the motion, which was seconded by Mr. Edwards and approved by roll-call vote (see record of votes above).

---

**Meeting Materials:**

1. SCSJ meeting presentation
2. SCSJ meeting minutes from December 12, 2024