

Special Commission on State Institutions

Meeting Minutes

May 8, 2025

3:00 PM - 5:00 PM

Meeting date: Thursday, May 8, 2025

Start time: 3:04PM

End time: 4:17 PM

Location: Virtual Meeting (Zoom)

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

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

Proceedings: Ms. Fracht, Commission Co-chair, called the meeting of the Special Commission on State Institutions to order at 3:04 PM. She announced that she'd be chairing today's meeting with Dr. Kate Benson, Commission Co-chair. 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 any questions posted by the audience in the Zoom platform would be addressed by The Center for Developmental Disabilities Evaluation and Research (CDDER) towards the end of the meeting. Lastly, she reminded everyone that today's meeting was scheduled for two hours and that there would be a break midway around 4:00PM.

Dr. Benson introduced herself as the Commission Co-chair and added that CART services would be available during the meeting and requested people, when speaking, to use as few acronyms as possible and a non-rushed pace, including briefly pausing to help the CART transcribe what is being

said. Lastly, Dr. Benson reminded everyone that a recording and minutes would be posted on the Commission's mass.gov website and the Commission's YouTube channel.

Ms. Fracht proceeded by outlining the meeting agenda, which included welcome and announcements, a recap of the last meeting, voting on the minutes from the last meeting, discussing recommendations for burials and burial locations, and voting on these and any remaining recommendations for records and records access and the framework for remembrance, as well as voting to adjourn.

Next Topic: Welcome & Announcements

Dr. Benson announced a memorial service on May 23rd for the 100th anniversary of the Belchertown State School Cemetery and mentioned that a recent fire took place at the former Fernald State School. She also noted that Ms. Jennifer Fuglestad from CDDER circulated the invitation for the memorial service to Commissioners and offered to answer any questions about the event.

Next Topic: Recap of 04/10/2025 Commission Meeting

Dr. Emily Lauer announced that Victor Hernandez, the Deputy Assistant Commissioner at the Massachusetts Department of Developmental Services, had retired following the previous meeting's announcement of his retirement. She then discussed the framework for remembrance, which included the idea of creating a disability museum. The Commission conducted a brainstorming session to evaluate the pros and cons of establishing either a physical or digital museum. Additionally, the Commission reviewed 17 recommendations aimed at improving the management, preservation, and access to institutional records. After thorough discussion, the Commission agreed to move forward with voting on all the recommendations except one, which required modifications. The remaining recommendations were accepted via vote.

Vote 1: Dr. Benson requested a motion to approve the minutes from the Commission's last meeting on April 10th, 2025. Mr. Bill Henning introduced the motion, which was seconded by Mr. Andrew Levrault and approved by roll-call vote (see record of votes above).

Next Topic: Stakeholder Feedback and Updates

Mr. Alex Green discussed voting on the final recommendations and his outreach to stakeholders who need to act on them. Mr. Green highlighted meetings with Senator Barrett and Representative Garballey, who praised the Commission's work and offered to support future legislation. He mentioned that letters will be sent to state agencies, informing them of the necessary action steps based on Senator Barrett's recommendation. He also noted the financial challenges of creating a museum and suggested a phased approach to this recommendation due to current economic constraints. Additionally, Green mentioned positive reactions from other stakeholders, including the Attorney General's office and the Secretary of State's office, who were surprised by the findings and eager to take action. Overall, Mr. Green felt that there was a strong sense of optimism and goodwill among the stakeholders he has met with to date.

Next Topic: Records and Records Access Proposed Recommendation - Modify Laws Regarding Restricted Medical Records

Mr. Samuel Edwards discussed a recommendation to modify laws regarding restricted medical records, allowing family members to access records within 50 years of an individual's death upon proving the person is deceased. He explained that the current court order process is confusing, complex, and can be a financial barrier for some families. This recommendation aims to simplify access for families. He shared a real-life example of an elderly woman who struggled with the court order process to access her aunt's institutional records and was unsuccessful in obtaining them.

Discussion:

- Mr. Andrew Levrault asked about the process for proving family relationships when accessing medical records, especially if last names differ.
 - Mr. Edwards responded that it would likely be handled by the MA State Archives on a case-by-case basis, with clear documentation required to prove the relationship. He noted that many people requesting records already have family history documents to support their records request claims.
- Mr. Green asked if HIPAA (Health Insurance Portability and Accountability Act) allows access to medical records 50 years after death and if other states have similar laws.
 - Mr. Edwards replied that HIPAA applies to active records, not archival ones, and suggested consulting legal experts to confirm this. He mentioned the need to research how other states handle this issue. Mr. Edwards emphasized that he is not a lawyer but an archivist, and would want to ensure any changes are legally sound.

Next Topic: Burials and Burial Locations Proposed Recommendations - Known & Unknown Burial Grounds

Dr. Benson presented a total of five recommendations for burials and burial locations, which were grouped into two subtopics, including known and unknown burial grounds and practices and laws related to the disabled dead.

The first recommendation for known and unknown burial grounds prioritized identifying unmarked graves on former institutional properties to understand the full scope of the issue, while ensuring some degree of accountability and memorialization, addressing long-standing concerns, and enabling future restoration and protection efforts.

The second recommendation proposed creating clear regulatory guidelines for investigating, restoring, and maintaining and protecting state institutional cemeteries in order to prevent future damage and violations and to standardize these practices, ensuring they incorporate disability justice principles.

The third recommendation suggested establishing a perpetual care fund for the long-term upkeep of these cemeteries, including grants for community groups to create memorials. Dr. Benson emphasized the importance of state responsibility and collaboration with disability advocacy organizations in maintaining these historic sites, as well as ensuring a respectful remembrance through such upkeep.

Next Topic: Burials and Burial Locations Proposed Recommendations - Disabled Dead Practices and Laws

Dr. Benson discussed the next set of recommendations around practices and laws related to the disabled dead. The first recommendation was to repeal Chapter 113 of the Massachusetts General Laws, which allows medical schools to use unclaimed bodies from state institutions for research. She noted that this recommendation had been briefly discussed by the Commission before. She further explained that using the bodies of disabled people without consent is problematic and outdated, as medical schools now have other legal, ethical ways to obtain cadavers, usually through voluntary body donation programs, such as anatomical gift programs. If the law is not changed, they recommend that the Attorney General intervene. She also emphasized that this recommendation would help protect the dignity and rights of those that died at institutions and were used for anatomical dissection.

The second recommendation was to request a formal apology from medical schools, institutions, and government agencies that used the bodies of deceased disabled individuals without consent. Part of this recommendation also suggests that these organizations should create a public registry of any human remains or related materials that continue to be in their possession. This would help loved ones and descendants locate and honor those who were taken for anatomical dissection and help in their healing process. These actions would also provide greater accountability and transparency for those who benefited from these practices, regardless of whether for financial and/or educational purposes.

Discussion:

- Mr. Green asked if the Attorney General should take short-term action to stop the use of unclaimed bodies from state institutions while waiting for the legislative process to repeal Chapter 113. Mr. Green also inquired about how often the practices under Chapter 113 continue to be used in modern times.
 - Ms. Fuglestad responded that Harvard's Anatomical Gift Program hasn't needed to request bodies since the late 1930s or early 1940s, as modern donation programs have met the needs of state medical schools.
- Mr. Levrault mentioned that Katie's law in Massachusetts, aimed at repealing outdated language about persons with disabilities, was stalled because they wanted to form a state commission to review all antiquated laws related to people with disabilities. He suggested considering whether the repeal of Chapter 113 could be included in this commission's work once it is formed.
- Dr. Benson agreed it was a good idea to address Chapter 113. She said they couldn't be sure someone wouldn't find the law and try to use it, so the safest option was to remove the wording completely. She also liked Mr. Green's idea of putting a temporary stop to using the law, just to be safe, even though no one was using it at the time.

Next Topic: Framework for Remembrance Proposed Recommendations - Museum & Memorialization Initiatives - Formal State Apology - Integrating Disability History into K-12 Education

Mr. Green shared three proposed recommendations for the framework for remembrance. The first recommendation was to create a statewide museum and resource center to honor former residents and share the history of disability rights and inclusion. He suggested forming a group to study whether this idea could work, both in physical and digital forms. He mentioned that there wasn't funding yet, but starting the conversation was still important. He believed this would show how meaningful the history was and help move the idea forward, even if it was just a first step. He also mentioned how the outcome of this recommendation could be a better model in comparison to the only existing physical museum on disability, which is part of a haunted house spectacle.

Mr. Green said they had talked about the next recommendation in March and most Commissioners agreed with it, but they hadn't taken a formal vote. The recommendation was for the Governor to issue a formal state apology. This apology would be for the neglect of institutional cemeteries, poor handling of records, and the overall harm done to people with disabilities in state institutions. He explained that while some people received care, many others were hurt, and the apology would recognize that history. It would also help survivors and families begin to heal and show the state's commitment to justice for people with disabilities. He mentioned that other states had made similar apologies, and it was time for theirs, especially since Massachusetts state had some of the earliest institutions.

Lastly, Mr. Green talked about the recommendation of adding disability history to K-12 education. He explained that states often choose important topics from their history to include in school lessons, and disability history should be one of them. He said this would help students learn about the past treatment of people with disabilities, the history of institutions, and how the disability rights movement grew. He believed it was important for students—especially those with disabilities—to see themselves in history. He also mentioned that other states had added topics like Holocaust education to their school programs, and many people he spoke with, including lawmakers and teachers, supported this idea.

Discussion:

Ms. Fracht said that teaching about disability in schools was more than just education—it was an important step toward ending the stigma around disability.

Vote 2: Before asking Commissioners for additional recommendations not yet considered by the group, Dr. Benson proposed that someone make a motion to approve the recommendations discussed during today's meeting on burials and burial locations and a framework for remembrance. Mr. Levrault made a motion to vote on these recommendations, which was seconded by Mr. James Cooney and approved by roll-call vote (see record of votes above).

Next Topic: Other Considerations and Recommendations

Ms. Fracht asked the Commission if there were any other considerations or recommendations they would like to discuss.

Discussion:

- Mr. Green said there was an important issue they couldn't decide on yet but should be ready to talk about next week when Senator Barrett and Representative Garballey would be present

during the Commission’s meeting. He explained that the Commission’s work would end in May after they submitted their report. Even though many people supported their efforts, the Commission wouldn’t exist anymore to follow up, do research, or hold others accountable. He raised the question of whether the Commission should continue in some smaller form to help keep things on track. He also mentioned that the Commission had received funding from the Legislature, which was used to pay CDDER for their work. If they wanted to keep the Commission going and continue working with CDDER, they would need to ask for more funding, which could be difficult since the state didn’t have much money. He suggested they talk to the Senator and Representative about how to move forward with both the funding and the future of the Commission.

Vote 3: Mr. Edwards asked a question about the process, wondering if they needed to vote on the records access recommendation. Dr. Benson thanked him for the reminder and explained that the recommendation was about allowing family members to access a deceased person’s medical records within 50 years of their death, as long as they could prove their identity and connection. She then asked if someone would make a motion to approve that recommendation. Mr. Green introduced the motion, which was seconded by Mr. Levraut and approved by roll-call vote (see record of votes above).

** FIVE-MINUTE BREAK (3:55PM – 4:00PM) **

Next Topic: Other Considerations and Recommendations (continued)

Discussion:

- Ms. Laurie Medeiros asked if there was a recommendation in the report to extend the Commission’s work, since she didn’t see it.
 - Dr. Benson responded that Mr. Green had mentioned it earlier as a possible recommendation, and they had briefly discussed the challenge of limited funding.
 - Ms. Medeiros then shared that she had seen a report from a Cambridge representative—possibly named Markovitz—who said Massachusetts had a \$9 billion rainy day fund. She acknowledged that the budget was tight and Medicaid was a concern, but she felt there might still be some room in the budget to support continuing the Commission’s work.
- Mr. Reggie Clark said the Commission shouldn’t make any decisions until they knew what the state budget would be and how much money would be available.
 - Dr. Benson agreed and said he made a good point. She added that they were watching the budget closely as they planned their next steps.

Next Topic: Additional Questions and Comments

Discussion:

- Ms. Fracht thanked everyone for attending, reminded them of the next full Commission meeting on May 15th, and informed them that CDDER would be following up with meeting information. She invited members to contact CDDER or the Commission’s leadership with any questions.

- Mr. Levrault asked if there was another full commission meeting on May 15th as well, and Ms. Fracht confirmed both upcoming meetings.
 - Mr. Clark said he wanted to know more about the recent fire at the former Fernald State School, including how many buildings were damaged.
 - Dr. Benson asked Ms. Fuglestad if she had shared the article with the Commission prior to today's meeting, and Ms. Fuglestad confirmed she had. Ms. Fuglestad also explained that there had been a series of fires at the former Fernald site since around November or December 2024. The State Fire Marshal had started an arson investigation because the fires were happening on Saturdays, showing a pattern. She also mentioned there was now a tip line and possibly a reward for information.
 - Mr. Clark reacted strongly, saying someone should go to jail for life.
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Next Topic: Adjourn Meeting

Vote 4: Mr. Clark introduced a motion to adjourn the meeting, 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 May 8, 2025
3. Fernald Arson Investigation-Boston Globe Article