

Special Commission on State Institutions

Meeting Minutes

April 10, 2025

3:00 PM - 5:00 PM

Meeting date: Thursday, April 10, 2025

Start time: 3:00PM

End time: 4:32 PM

Location: Virtual Meeting (Zoom)

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

* (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 3:00 PM. She announced that Dr. Kate Benson, Commission Co-chair, was absent and that Mr. Alex Green, Commission Vice Chair, would be co-facilitating the meeting with her today. 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 from the Zoom Q & A would be addressed by The Center for Developmental Disabilities Evaluation and Research (CDDER) towards the end of the meeting and that there would be a break midway around 4:00PM.

Ms. Jennifer Fuglestad from CDDER from UMass Chan Medical School 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, Ms. Fuglestad reminded everyone that a recording and minutes would be posted on the Commission's mass.gov website and the Commission's YouTube channel.

Next Topic: Welcome & Announcements

Ms. Fracht welcomed Camille Karabaich, a representative of the Massachusetts Office on Disability (MOD), that replaced Mary Mahon McCauley who recently retired. Ms. Karabaich introduced herself and expressed her interest and enthusiasm to learning more about the Commission.

Next Topic: Recap of 03/13/2025 Commission Meeting

After the welcome and announcements, Ms. Fracht introduced Dr. Emily Lauer from CDDER to provide a recap of what was talked about during the last Commission meeting held on March 13th, 2025. Dr. Lauer reported that the Commission had voted to approve Mr. Green as the Commission's Vice Chair. The schedule for upcoming Commission meetings was also discussed and the Commission decided to hold the next meeting virtually as an accommodation to ensure accessibility, as the Virtual Meeting Law had not yet been extended at that time. Since then, the Virtual Meeting Law was extended. The Commission also discussed four recommendations related to the Framework for Remembrance, including the creation of a Disability History Museum, a perpetual care fund, a statewide Day of Remembrance, and a formal apology from the State of Massachusetts for past neglect and harm caused by state institutions.

Vote 1: Ms. Fracht requested a motion to approve the minutes from the Commission's last meeting on March 13th, 2025. Mr. James Cooney introduced the motion, which was seconded by Mr. Bill Henning and approved by roll-call vote (see record of votes above).

Next Topic: Upcoming Meeting Schedule

Ms. Fracht discussed the schedule for upcoming Commission meetings, noting that the next meeting was set for May 8th. She mentioned a doodle poll sent by CDDER to check availability for a potential meeting on May 15th to finalize recommendations before the June 1st submission to the legislature. She emphasized the importance of having a quorum and confirmed that an invitation for the May 15th meeting would be sent out.

Next Topic: Announcement of Victor Hernandez' Retirement

Mr. Green announced that it was Victor Hernandez, Deputy Assistant Commissioner at Massachusetts Department of Developmental Services, last day before retirement. He praised Victor for his significant contributions to the Commission, highlighting his 30-plus years of experience, grace, patience, and deep understanding in serving the disabled community. Mr. Green expressed deep gratitude and wished Victor well in his retirement.

Next Topic: Framework for Remembrance Recommendation - Disability Museum

Mr. Green discussed the plan for the upcoming meetings, focusing on reviewing recommendations for the executive summary of their report. He mentioned that they would evaluate various recommendations, deciding which ones are straightforward to adopt and refining their language over the next few weeks. He acknowledged that some recommendations might require more in-depth discussion to reach a consensus.

He specifically highlighted a previous discussion about recommending the creation of a disability museum. This museum would preserve the history of residents from state institutions, highlight the independent living movement, and provide resources for former patients and their families. Mr. Green emphasized the importance of discussing the pros and cons of this idea, whether it should be a physical or digital space, and using a new online whiteboard tool to capture everyone's thoughts. Mr. Green then opened up the meeting for discussion.

Discussion:

- Ms. Laurie Medeiros shared her thoughts on the importance of preserving historical records, inspired by her work with Martha Ziegler. She emphasized the value of both physical and digital museums, noting that each has unique accessibility strengths. She compared the impact of visiting a Holocaust memorial to the potential impact of a physical museum, highlighting the powerful, experiential nature of physical spaces. However, she also recognized the importance of digital access for those who might find it difficult to visit a physical location.
 - Mr. Green appreciated her clarity and summarized her points, agreeing on the importance of memorialization and the potential benefits of having both physical and digital components.
- Mr. Vesper Moore discussed the complexities and requirements of establishing a museum, emphasizing that it can be very time-consuming. He highlighted the need to decide whether the space should be a traditional museum, a community space, an online space, or a combination of these. He pointed out that each option has its own set of pros and cons, particularly in terms of continuing education and awareness.
 - Mr. Green asked about the financial and operational support needed for such a project.
 - Mr. Moore explained that a museum would require full-time employees to oversee operations, consultants for handling specific environmental conditions, and potential architectural changes depending on the building used. He stressed that these considerations involve significant planning and resources.
- Mr. Henning agreed with Ms. Medeiros' positive points about the museum idea and found it exciting. However, he was concerned about the high costs and limited state and federal funding. He suggested starting a process to build on the idea and proposed a feasibility study instead of a legislative study, which he believed would be more effective and provide more accountability.
 - Mr. Green promised to support Mr. Henning's proposed approach.
- Mr. Green found the discussion helpful and clarifying. He mentioned that this topic would be revisited in future meetings. He planned to give the feedback to the report work group to create different language options for this set of recommendations. Lastly, he encouraged anyone who didn't speak to email their thoughts to the CDDER team at scsi_support@umassmed.edu.

Next Topic: Records and Records Access Recommendations - Changes to Management, Preservation, and Access Rules – Issuing a Moratorium on Destruction of Records

Mr. Green explained that there were a total of 17 recommendations for this topic area that were categorized into four groups, including changes to management, preservation, and access rules; changes to laws around record access; access improvements for former patients/residents or their

families and researchers, and creating a pathway for the return of institutional records to the MA State Archives.

Mr. Green started the discussion by explaining the changes to management, preservation, and access rules. He simplified the previous proposal and highlighted a key observation from the CDDER team, which was that some state agencies are required by law to destroy records instead of transferring them to the appropriate place. As a result, he believed the first recommendation to prioritize was putting into effect a moratorium to stop the destruction of records until new rules are implemented, ensuring no records are lost. He asked if anyone had objections to starting with this recommendation.

Discussion:

- Mr. Samuel Edwards didn't object to the recommendation around the moratorium on record destruction but felt it needed more clarity. He pointed out that many office records aren't historically significant and don't need long-term retention.
 - Mr. Green agreed and suggested discussing ways to manage expectations and deciding the moratorium's length and authority. He acknowledged the potential difficulty in separating documents initially and the risk of retaining unnecessary records.
- Ms. Medeiros was curious about how to determine which records are important to save. She mentioned the PBS show "Finding Your Roots" and wondered if there was an expert who could advise on what to preserve and what could be digitized. She felt that an expert's perspective would be valuable in making these decisions.

Next Topic: Records and Records Access Recommendations - Changes to Management, Preservation, and Access Rules – Identify Key Record Sub-Categories for Retention

Mr. Green moved to the next recommendation, which was to identify key record subcategories to determine what should be retained and what shouldn't. He suggested establishing these categories and consulting with organizations or agencies that have representative voices and good insights. He asked for recommendations on which organizations to consult, such as the Massachusetts on Disability (MOD), Massachusetts Developmental Disabilities Council (MDDC), or Massachusetts Association for Mental Health (MAMH).

Discussion:

- Mr. Moore admitted he didn't know much about public records requirements. He mentioned reaching out to a potential contact, but they might not be available. He recommended consulting the Organization for American Historians, which he had encountered at a conference. He believed they could provide guidance and suggested presenting findings at their conference. He noted that record destruction requirements might vary by state and thought the Organization for American Historians could be a helpful external entity.

Next Topic: Records and Records Access Recommendations - Changes to Management, Preservation, and Access Rules – Revise Document Retention Schedules

Mr. Green introduced the third recommendation, which was to revise the residential schedules. This would allow for the destruction of documents again, but with clear guidelines on what to keep and what to discard, and a new timeline. He emphasized the importance of consulting the disability community in this process. He trusted the MA State Archives to guide the process due to their experience with sensitive documents.

Discussion:

- Mr. Edwards questioned whether historians were the right experts to consult, as they interpret documents rather than manage them. He suggested that the archival profession, which has theories and ethical guidelines on what to keep or discard, would be a better avenue to pursue.
- Mr. Cooney expressed concern about unintended consequences, such as accumulating stacks of useless information that can't be accessed in an organized way. He echoed Mr. Edward's point about the need for clear definitions of content and time frames to ensure organized processes and information, along with implementable instructions for facilities and institutions.
- Mr. Green asked Mr. Edwards to brainstorm with the MA State Archives on the right wording for the recommendations. He emphasized the importance of identifying essential steps in the documents to avoid any issues. He referenced the warehouse scene from Indiana Jones to illustrate the need for organized information. He noted there were no strong objections to the plan and aimed to finalize the language soon. He invited anyone with ethical concerns to inform CDDER and moved on to the next set of recommendations.

Next Topic: Records and Records Access Recommendations - Changes to Management, Preservation, and Access Rules – Develop a Clear Workflow for Record Requests - Delegate Redaction and Release Decisions to Archives - Expand Archives' Staffing

Mr. Green discussed three interrelated recommendations around records and records access. The first one was to develop a clear workflow for record requests to ensure consistent processes across agencies and allow Archives to confirm if they hold specific records. This would streamline access and improve transparency. The second recommendation suggests that the MA State Archives handle the process of redacting sensitive information from records, as they already do this regularly. The third recommendation proposed included expanding MA State Archives' staffing to manage the increased workload, especially given the volume of requests. He invited feedback and thanked Mr. Edwards for his contributions.

Discussion:

- Ms. Medeiros asked who would hire the additional MA State Archives full-time staff.
 - Mr. Green clarified that the recommendation was to expand MA State Archives' staff and asked Mr. Edwards to identify the responsible person.
 - Mr. Edwards suggested Kaitlin Ramos, the new curator of MA State Archives.
 - Mr. Green agreed and noted they would need to include specific language about where the staffing requests should go, possibly in the next budget or legislative proposal.
- Ms. Medeiros pointed out that funding for the project doesn't have to come solely from the state budget or legislators. She suggested exploring various grants, mentioning the Cummings

Foundation as an example. She emphasized the importance of considering multiple funding sources to support the endeavor.

- Mr. Green agreed, noting the complexity of the issues and the need for flexible solutions. He mentioned other potential funding avenues, such as reallocating funds by the Secretary of the Commonwealth, executive orders from the Governor, and grants obtained by organizations like the MA State Archives.
- Mr. Edwards questioned recommendation 5, which suggested delegating redaction and releasing decisions to the MA State Archives. He clarified that it should focus on records already in the MA State Archives' collections, not all records from DMH and DDS.
 - Mr. Green agreed and asked Mr. Edwards to flag this issue. Mr. Green also sought clarity on who has the authority to order redactions.
 - Mr. Edwards explained that currently, the MA State Archives scans records and sends them to DMH or DDS for redaction decisions.
 - Mr. Green emphasized the need to streamline this process to avoid the issue of records being passed between agencies without resolution.

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

Next Topic: Records and Records Access Recommendations - Changes to Laws Around Record Access – Pass the Sunset Law - Implement Use Restrictions for Public Records - Modify Laws Regarding Restricted Medical Records

Mr. Green discussed the Sunset Law, which would open institutional records after 75 years, except for medical records protected by Health Insurance Portability and Accountability Act (HIPAA). He emphasized that the law applies to records in the MA State Archives, not active DDS or DMH records. He also recommended implementing use restrictions for public records to prevent misuse, suggesting that the MA State Archives develop rules for respectful use. Lastly, he proposed modifying laws to allow family members to access medical records within 50 years of a relative's death, but not researchers. He noted an error in the original document, clarifying that the intent was to help family members access records, not researchers. He asked if there were any objections to the first two recommendations.

Discussion:

- Mr. Andrew Levrault asked for clarification on recommendation 8 (Implement Use Restrictions for Public Records), wondering how public records could have usage restrictions.
 - Mr. Edwards explained that the MA State Archives already has restrictions for various reasons, such as fragility, security, and privacy. He described different levels of restriction, from highly restricted records to those freely accessible online.
 - Mr. Levrault understood and appreciated the explanation, realizing that policing online posting of records would be challenging.
- Ms. Camille Karabaich asked if recommendation 7 (Pass the Sunset Law) would treat records of people with disabilities the same as those without disabilities.
 - Mr. Edwards explained that the law applies to all records over 75 years old, except for medical records, which are protected by HIPAA for 50 years after a person's death.

- Mr. Green added that the bill had been refined to specifically address institutional records and align with the Commission's definitions, ensuring it doesn't apply to active DDS and DMH records. He acknowledged the complexity of the bill.

Next Topic: Records and Records Access Recommendations - Improve Access to Records – Post Clear Instructions for Records Access - Create a Searchable Public Inventory - Train Peer Guides for Individuals with Disabilities

Before discussing the next set of recommendations, Mr. Green explained to the Commission that they would vote on the general direction of the recommendations, not the exact wording, as revisions were needed and that recommendation 9 (Modify Laws Regarding Restricted Medical Records) would be removed and revisited the next time they meet due to the error.

He then discussed improving access to records, which had been very difficult for many people. The first recommendation was to post clear, consistent instructions for records access across all relevant websites. The second was to create a searchable public inventory to help people know if records exist before spending time and money. This inventory would not include names but would indicate the types of records available. The third recommendation, inspired by former SCSI co-chair and current Commissioner, Evelyn Mateo, was to train peer guides to assist individuals with disabilities in accessing records, ensuring they have support during the process. Mr. Green invited feedback on these recommendations.

Discussion:

- Ms. Medeiros asked where the 12 recommendations would go and about the next steps after submitting the recommendations.
 - Mr. Green explained that they would be sent to the legislature, the president of the Senate, the Speaker of the House, all members and clerks of those groups, and the Governor. He said they would discuss enforcement and oversight next month, possibly asking the Commission to continue its work or having someone file a bill. He emphasized the importance of accountability and mentioned that the circulated documents specify which agencies or individuals should take up the work.
 - Ms. Medeiros suggested including language to ensure implementation and follow-up, sharing a past experience where a bill passed but lacked mechanisms for checking implementation.
 - Mr. Green agreed and assured that they would work on crafting specific recommendations to prevent the work from being forgotten.

Next Topic: Records and Records Access Recommendations - Improve Access to Records – Waive Probate Fees and Simplify Filing for Institutional Records - Clarify Access to Institutional Cemetery Burial Records

Mr. Green discussed two final recommendations for improving access to records. The first one was about waiving probate fees and simplifying filing instructions for accessing records of deceased individuals. The Mental Health Legal Advisors Committee would oversee this implementation. The second recommendation involved clarifying that burial records in state institutional cemeteries are

vital records, not medical records, to make them accessible. This follows a similar decision in Washington State. These recommendations aim to make it easier for people to access important records.

Discussion:

- Ms. Medeiros asked if considering burial records as vital records would only reveal that someone died, not their burial location?
 - Mr. Green clarified that the recommendation would include burial locations as part of the vital records. While it might not specify the exact spot, it would help people get close enough to locate their loved ones.

Next Topic: Records and Records Access - Create Pathways for the Return of Institutional Records- Temporary Moratorium on Prosecution for Returning Documents - Cease-and-Desist Order for Online Marketplaces - Demand the Return of Documents from Private Entities

Mr. Green talked about the problem of important records being scattered in different places, like private universities, local museums, and even with individuals. People might be afraid to return these records because they fear getting into trouble with the law. To address this, he provided an explanation for the following three recommendations. First, the Attorney General and Archives should promise not to prosecute anyone who returns these records. This way, people can return them without fear. Second, the Attorney General should tell online marketplaces to stop selling these records because it violates privacy. Lastly, the MA State Archives should ask institutions and individuals to return any records they have to centralize them. This will help people find information about their deceased loved ones more easily.

Discussion:

- Ms. Medeiros suggested adding a statement to clarify that the Massachusetts legislature has deemed the records as property of the Massachusetts State Archives. This would avoid implying that the records were taken from the MA State Archives.
 - Mr. Green agreed and praised Ms. Medeiros' suggestion, asking Mr. Edwards to help with the modifications.
 - Mr. Edwards agreed to assist.

Next Topic: What else should the Commission consider?

Mr. Green emphasized the importance of the recommendations, which summarize a year's work addressing issues around records from institutions. He acknowledged the complexity and legal nature of the topic but stressed the deep human connection and the need to help people quickly. He invited feedback on anything missing or needing further explanation, aiming to present the 17 recommendations clearly and effectively. He highlighted the goal of making a positive impact and addressing the most painful and damaging issues first.

Mr. Green informed the group that in the next two meetings in May, they would revisit the Framework for Remembrance recommendations and conduct votes similar to the current ones.

They would also focus on the cemetery section and include Ms. Mederios' comments on modifying laws related to medical experimentation and autopsies on deceased individuals from institutions.

Mr. Green suggested reviewing earlier slides and proposed a motion to endorse the strategies presented, emphasizing the importance of the recommendations without endorsing the exact wording. He acknowledged the need for some back-and-forth discussion and asked if voting should be done in chunks or all at once.

Discussion:

- Mr. Henning mentioned that they had thoroughly reviewed everything and suggested that they could proceed as a group without repeating the same discussion.
 - Mr. Green agreed and noted the removal of recommendation 9 (Modify Laws Regarding Restricted Medical Records) from the discussion.
- Mr. Reggie Clark emphasized the importance of ensuring that people who receive copies of records understand why they want them and follow the rules. He stressed that if others were in their shoes, they would understand the significance of having access to these records.
 - Mr. Green appreciated Mr. Clark's comments and thanked him for his contributions.

Vote 2: Mr. Green asked for some voting language on the approval of the recommendations, excluding recommendation 9. Mr. Moore made a motion to vote on all recommendations, except for recommendation 9, which was seconded by Mr. Edwards and approved by roll-call vote (see record of votes above).

Next Topic: Additional Questions and Comments

Discussion: Ms. Fracht reminded everyone that the next meeting was scheduled for May 8th and confirmed that there would be another meeting on May 15th.

Next Topic: Adjourn Meeting

Vote 3: Ms. Fracht asked if there was a motion to adjourn. Mr. Levrault introduced the motion, which was seconded by Mr. Henning and approved by roll-call vote (see record of votes above).

Meeting Materials:

1. SCSJ meeting presentation
2. SCSJ meeting minutes from March 13, 2025