

Special Commission on State Institutions

Meeting Minutes

February 13, 2025

3:00 PM - 5:00 PM

Meeting date: Thursday, February 13, 2025

Start time: 3:00PM

End time: 4:58PM

Location: Virtual Meeting (Zoom)

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

* (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: Announcements

Ms. Benson announced that Commissioner Mary Mahon McCauley, a representative of the Massachusetts Office on Disability (MOD), will retire and step down from the Special Commission at the end of February 2025. Ms. Benson thanked Mary on behalf of the Commission for her contributions, as well as notified Commissioners that a new representative from MOD would take Mary's place.

Next Topic: Recap of 01/23/2025 Commission Meeting

After the announcements, 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 January 23rd, 2025. Dr. Lauer's recap included the following:

SCSI Final Report Plan: The Commission discussed the need to review the final report from CDDER, including identifying questions, creating recommendations, and writing those recommendations for the Commission's final report, which is due June 1st, 2025. They talked about forming a Report Working Group to assist with this task and support the larger Commission to develop and finalize recommendations and the report overall. The Commission also approved a monthly meeting schedule through May 2025, allowing sufficient time for the Commission to develop its recommendations and meet the report deadline.

CDDER Report & Opportunities for Consideration: In a presentation, CDDER explained the informational report they delivered to the Commission in mid-January, covering its main areas, structure, and opportunities for considerations around records and records access and burial and burial locations. The Commission discussed the CDDER report's content, provided feedback, and began identifying potential areas for recommendations and next steps. It was agreed that the discussion on these opportunities would continue in the February meeting.

Vote 1: Ms. Benson requested a motion to approve the minutes from the Commission's last meeting on January 23, 2025. Mr. Alex Green introduced the motion, which was seconded by Mr. Bill Henning and approved by roll-call vote (see record of votes above).

Next Topic: Purpose of Special Commission

To remind Commissioners of the origins, goals, and significance of their work, Mr. Green provided a brief overview of the Commission's background, purpose, and mission. Other goals of providing this context were to reinforce the collective commitment to the Commission's objectives and prepare Commissioners to make informed recommendations based on their findings from the CDDER report and their own personal experiences and knowledge.

Mr. Green explained that the Special Commission was established during the pandemic to address the historical and ongoing issues related to former institutional sites in Massachusetts. It was noted that these sites have a complex history involving both positive contributions and significant negative impacts on individuals with disabilities. The Commission was formed after protests and legislative support from Senator Mike Barrett and Representative Sean Garballey, who recognized the need for public awareness and education about this history. The main goals of the Commission are to investigate the history of these institutions, address issues related to records and cemeteries and make recommendations for public awareness and education.

The main goals of the Commission are to investigate the history of these institutions, address issues related to records and cemeteries and make recommendations for public awareness and education. The Commission, which is unique in having a majority of disabled members, has been working with CDDER to gather information and develop a comprehensive report. This report will be presented to the legislature and the governor, outlining findings and suggesting actions to ensure

the history is acknowledged and learned from. The Commission is proud of its rapid progress and significant work, and it aims to continue making impactful recommendations for the future.

Discussion:

1. Sister Linda Bessom expressed how much she has learned from the important discussions the Commission has fostered. She also reminded everyone how crucial it is that the State follows through with the Commission's recommendations as the Commission's report is vital to both change and stopping the past from repeating itself. She expressed her recent concerns about how recent executive orders from the President might impact the Commission's work in Massachusetts and that the Commission needs to ensure its efforts aren't ignored due to political changes.
 - a. In response to Sister Linda Bessom's concerns, Mr. Green emphasized that it's okay for the Commission not to have all the answers and encouraged open discussion within the Commission. He suggested forming a team to meet with legislators individually or in briefings to ensure they understand the report's findings and recommendations. He also acknowledged the broader national concerns but stressed the importance of the Commission's work in shaping mindsets and influencing state officials based on their findings.
 1. Sister Linda Bessom state she has experience in legislative advocacy and would be happy to help by contacting representatives and senators, attending hearings, and supporting the Commission's efforts.
 - b. Dr. Lauer also encouraged the Commission to highlight important historical lessons and advocate for the rights of people with disabilities, emphasizing the need to restate protections even if they are already covered by existing laws like Olmstead and the Americans with Disabilities Act.

Next Topic: The Summary Report

What is the purpose of a summary report and who is it for?

- Mr. Green emphasized the importance of creating a summary of the CDDER report, as it will be more widely read than the full report. This summary will highlight the key points, explain the Commission's background, work, findings, and recommendations, ensuring that the core messages are effectively communicated to a broader audience. The summary of the report will be formally delivered to legislative leaders and made publicly available online. The goal is to educate people by clearly and concisely presenting the key findings and recommendations, such as the difficulty people have had in obtaining records about their relatives who lived in institutions.

What types of things can be said in the summary report?

- Mr. Green emphasized that the summary of the report should present an informed opinion rather than just facts. He explained that while the detailed report provides the historical facts, the summary should convey the Commission's conclusions and recommendations based on those facts. He encouraged the Commission to be bold in expressing their opinions and the need for action, similar to how past reports have evoked a sense of injustice and determination to act.

How is the Commission going to create the summary report?

- Mr. Green explained that the Commission will process the information from CDDER's report into concise statements and recommendations. The Report Working Group will organize these ideas and bring them back to the larger Commission for feedback and revisions. The goal is to create a final summary that all Commissioners agree on, which will be shared after a vote, over the next four months.

What are the key areas for the summary report?

- Mr. Green outlined four key areas for the Commission's summary: what they did, what they found, what people need to know, and what actions should be taken. He highlighted the importance of sharing cemetery records and addressing difficulties in obtaining records. The summary should also include recommendations, such as teaching this history in schools. He emphasized that all these points are interconnected and should be clearly communicated.

What else should the Commission do?

- Mr. Green suggested reaching out to the senator and representative who initiated the Commission to add their perspectives to the report. He also proposed creating a short version of the report for journalists in a press release and considering additional actions like meeting with state leaders to discuss findings. The goal is to educate people clearly and effectively, and he encouraged the group to discuss the best ways to achieve this.

Discussion on Summary Report Writing Style:

- Mr. Green emphasized the importance of using plain language in the summary to make it more accessible, despite its bluntness. He acknowledged that plain language can make difficult topics harder to read emotionally but suggested including a warning. He opened the topic for discussion and proposed a vote on whether to use plain language for the summary.
 1. Mr. Samuel Edwards supported having a plain language summary but suggested also including a more detailed version for technical recommendations related to specific laws, especially around records and records access.
 2. Mr. Henning agreed with Mr. Edwards' suggestion of having both a plain language summary and a more detailed version of it with depth and valid resources for legislators and the public. He believes both versions are necessary to represent the Commission effectively.
 3. Ms. Mary Mahon McCauley supports having a plain language summary for clarity and accessibility but also sees the need for a more technical version for legislators and legal professionals. She believes both formats are important, especially for recommendations, to ensure comprehensive communication.
 4. Sister Linda Bessom suggested including real-life stories in the report, with identities protected, to emotionally engage legislators and support the recommendations. She believes personal stories can inspire legislative action and show the importance of the Commission's work.
 5. Dr. Lauer suggested framing the discussion as style instructions for the Report Working Group, emphasizing the need for both plain language and more technical language for different audiences. She indicated that a vote might not be necessary at this point, but the working group should consider these guidelines while drafting the summary report.

1. This proposed approach was agreed upon by the Commission.
- In addition to the above, Mr. Green explained that there are two ways to refer to disabilities: "people with disabilities" and "disabled people," each with a different emphasis. He stressed the importance of choosing one consistent term for the report to ensure clarity and comfort for everyone involved.
 1. Ms. Benson believes using people-first language ("individuals with disabilities") is important for the Commission, though historical context may require different terminology. She emphasized the subtle but significant impact of this choice.
 2. Ms. Mahon McCauley prefers using "people with disabilities" language, emphasizing people-first terms, but, like Ms. Benson, understands that historical references might use different wording. She later reflected on how people with disabilities were often referred to by their diagnoses in medical settings, which she found disrespectful. She identifies as a disabled person and suggests using both "disabled person" and "differently abled," while ensuring the term "disability" is included for legal clarity.
 3. Mr. Reggie Clark also prefers the term "people with disabilities" and emphasizes the importance of knowing where records are kept and focusing on local issues.
 4. Mr. Henning noted that while he doesn't have a disability, he finds the interchangeable use of terms interesting and abstains from the discussion for personal reasons.
 5. Mr. Edwards prefers disability-first language as it boldly claims disability as an identity and a political category, feeling more direct to him.
 6. Sister Linda Bessom appreciates the discussion and points out that not using inclusive language has led to human rights violations. She suggests using respectful terms in official documents to avoid disrespecting people with disabilities and proposes using "people with different abilities" instead to account for people with apparent and non-apparent disabilities.
 7. Like the approach that was agreed upon regarding the use of both plain and report-writing language, Ms. Benson emphasized the importance of the Report Writing Group selecting language that fits the context and ensures everyone's comfort. She mentioned that the group will consider this as they assemble the report.

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

Next Topic: Impact on Today

Report Work Group Meeting Takeaways:

- After the break, Mr. Green provided some key takeaways from the Report Work Group meeting that was held recently. During the meeting, work group members shared the different ways that the things found in the CDDER report have an impact on disabled peoples' lives today. Specifically, the Work Group highlighted the importance of making meaningful recommendations for the report by connecting historical context to present-day relevance. Members also emphasized honoring past efforts, the need for education, and the risk of repeating history if these stories remain untold.

SCSI Outcome Examples:

- Next, a few work group members provided some recommendations around a framework for remembrance in the form of a museum, cemetery restoration related to burials and burial

locations, and patron records access from the Massachusetts State Archives.

Recommendations included key steps needed to be put into place to make them happen.

- **Museums:** In her presentation, Ms. Benson emphasized that the focus should be on creating educational opportunities rather than just building museums. This involves securing funding, organizing collections, collaborating with stakeholders, and deciding whether to create a physical museum, a virtual museum, or an educational network, and then determining how to share the final product with the public.
- **Massachusetts State Archives Patron Records Access:** Mr. Edwards discussed improving access to records based on his experience as a reference archivist. He suggested balancing privacy concerns with access needs, similar to how prison records are managed, and proposed clearer workflows with agencies like DMH and DDS. He also mentioned the idea of using proxies to navigate legal issues and suggested having on-site archivists to better manage and transfer records. These recommendations aim to make records more accessible while respecting privacy.
- **Cemetery Restoration:** Ms. Benson discussed a plan for cemetery work and restoration. The plan includes installing signage to inform the public about cemeteries and their history and the people who are buried there, sharing best practices for caretaking unmarked cemeteries, and providing consultation to cities and towns on restoration. It also emphasizes collaboration and support from stakeholders to ensure successful restoration efforts.

Discussion on SCSI Outcome Examples:

1. Mr. Andrew Levrault asked about the process for accessing prison records after an individual's death, specifically if access is immediate.
 - Mr. Edwards clarified that patrons seeking prison records need to provide the name of the person and proof of death, such as a death record or obituary. Upon receipt of such documentation, the Massachusetts State Archives then scans the records and makes and necessary redactions before providing access to the person requesting access.
2. Mr. Levrault followed up on his first question asking whether HIPAA (Health Insurance Portability and Accountability Act) restrictions would apply to these records, given the 50-year requirement and the involvement of DDS and DDH as covered entities.
 - Mr. Edwards explained that, to his understanding, HIPAA pertains to active medical records, not inactive ones. He mentioned that records at the Archives are considered inactive and historical, but acknowledged that more research might be needed to confirm this.

Discussion on Impact on Today:

Mr. Green proceeded to facilitate a discussion around key elements the Commission should consider when formulating their recommendations, as well as the next steps for the Commission. Specifically, he emphasized the importance of brainstorming and breaking down complex ideas and recommendations into manageable parts to be able to further analyze and identify other things to consider and perhaps incorporate in the recommendations. He encouraged all Commissioners to freely share their ideas on what they want to achieve in this phase of their work, including specific goals and priorities, so the Report Work Group can address them accordingly.

- Ms. Mahon McCauley expressed her gratitude for the learning experience on the Records Working Group and emphasized the need for a consistent process in obtaining records. She noted that family members often face different procedures depending on the institution or time period. She shared her personal experience of trying to obtain records for a family member who was at Medfield State Hospital in the 1950s and '60s, highlighting the challenges and delays in accessing these records. She suggested that a more consistent and timely process would be beneficial for family members.
 - Mr. Green agreed with Ms. Mahon McCauley's suggestion for a simple and consistent process to access records. To highlight current inconsistencies in the records access process, Mr. Green shared a story about someone who had to write an unexpected letter to a judge explaining why they needed records of a deceased relative, calling it unfair and emotionally difficult.
- Sister Linda Bessom asked who will oversee the implementation of the Commission's recommendations and how accountability will be ensured to prevent the report from being forgotten. She emphasized the importance of ongoing provisions to ensure the recommendations are carried out and questioned the value of the work if it isn't implemented.
 - Mr. Green acknowledged the importance of Sister Linda Bessom's question about accountability. He shared an example from the 1990s when recommendations from a similar commission were not followed through. He suggested that the current commission might need to continue in some form to ensure accountability and proposed asking CDDER and supportive legislators for ideas on how to achieve this. He emphasized the need for ongoing efforts to ensure the work gets done and doesn't just end up as an unused report.
 - Mr. Levrault who serves as a member of the permanent commission on the Status of Persons with Disabilities, suggested adopting a similar model of this commission which has an executive director and working groups, as a way to ensure ongoing accountability and secure funding for the recommendations. He proposed this as a potential recommendation for the State Commission on State Institutions to consider.
 - Mr. Green agreed that the commission model Andrew mentioned is a great idea. He suggested discussing it in a future meeting and emphasized the importance of ensuring there is funding and resources to implement the recommendations, avoiding the issue of an "unfunded mandate." He proposed that the records or report group, along with CDDER, should think through these details.
- Mr. Henning emphasized the importance of keeping the history of dehumanization of people with disabilities alive to prevent it from happening again. He mentioned that while records and cemeteries are important, the mission should be about making this history relevant today. He suggested that the group needs to focus on how to achieve this goal in a meaningful way.
 - Mr. Green agreed with Mr. Henning's point and emphasized the importance of educating people about past mistakes to prevent them from happening again. He suggested exploring various options, such as incorporating this history into public school curricula or funding speakers, to ensure people are informed.
 - In support of Mr. Henning's concern, Mr. Edwards stressed that accessing historical records is crucial for understanding past mistreatment and discrimination, especially since many people from those times are no longer alive to share their stories. He

believes that records are essential for learning about and preventing these injustices from happening again.

- Ms. Evelyn Mateo shared that she has learned a lot from the Commission, including that she could access her records, which she didn't know until two years ago. Growing up in state custody, she went through various foster homes and hospitals without knowing she had a record let alone the right to access it. She emphasized the importance of being able to access this information, as it has increased her understanding of her own upbringing. Ms. Mateo found it challenging to navigate the process of obtaining her records, and through her own professional experience, has met several people who have shared similar difficulties with this process or are simply unaware that they have the right to access their own records or of the steps to access them. She also recommends for anyone seeking their records to have a support team when doing so as it can be a very emotional and traumatic experience learning about one's own past in the system.
 - Mr. Green identified a couple possible recommendations for consideration from Ms. Mateo's direct and indirect experience with records access, including addressing the issue of ensuring access to a person's comprehensive record, especially when the person has received services across multiple settings and providers throughout their life, and how to educate and outreach to people who were once served or continue to be served by state agencies in a manner that is sensitive and not traumatizing.
- Ms. Mahon McCauley made two main points. Her first point, which is aligned with what Ms. Mateo shared, focuses on the importance of people knowing they have the right to access their records and having a consistent process to do so. Second, she highlighted the need to give dignity to individuals who died in institutions with unmarked graves, stressing the importance of acknowledging and addressing this issue in the Commission's final report.
- Mr. James Cooney suggested that agency practices should include making staff aware of the history and experiences of individuals, emphasizing human rights. He recommended that agency staff should help advocate both current individuals and families seeking historical records, and that this responsibility should be clearly defined as part of their roles.

Next Topic: Additional Questions and Comments

Discussion: Before adjourning the meeting, Ms. Benson reminded everyone about the next meeting in March, mentioned that the Report Writing Group would meet in the meantime, and invited members to contact the Commission with any questions.

Next Topic: Adjourn Meeting

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

Meeting Materials:

1. SCSJ meeting presentation
2. SCSJ meeting minutes from January 23, 2025