

## Special Commission on State Institutions

### Meeting Minutes

March 13, 2025

3:00 PM - 5:00 PM

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Meeting date: Thursday, March 13, 2025

Start time: 3:00PM

End time: 4:34PM

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1	Vote 2	Vote 3	Vote 4
Alex Green – The Arc of Massachusetts, designee	X	A	X	X
Andrew Levrault – Disabled Persons Protection Commission (DPPC)	-	-	-	-
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	X	-	X
Brenda Rankin – Wrentham Developmental Center	X	X	O	-
Elise Aronne – Wrentham Developmental Center	-	-	-	-
Evelyn Mateo – Department of Mental Health (DMH)	-	-	-	-
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	-	-	-	-
Camille Karabaich – Massachusetts Office on Disability (MOD)	-	-	-	-
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	-	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	X	X	X

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

**Proceedings:** Dr. 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, state their name before speaking, and speak at a non-rushed pace. 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. Dr. 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 and the Commission’s YouTube channel.

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**Next Topic:** Welcome & Announcements

Dr. Benson welcomed Camille Karabaich, a representative of the Massachusetts Office on Disability (MOD), that replaced Mary Mahon McCauley who recently retired. Since Ms. Karabaich was not present, Dr. Benson said she’d give her the opportunity to introduce herself at the next Commission meeting.

Dr. Benson also announced the departure of Mr. Matt Millett, former Commission co-chair, due to personal reasons, and thanked him for his support throughout the Commission. Mr. Victor Hernandez, Massachusetts Department of Developmental Services Deputy Assistant Commissioner, announced that Ms. Anne Fracht, from DDS, expressed interest in being the new co-chair, highlighting her long-standing advocacy and commitment to DDS and other advisory boards. Both he and the DDS Commissioner are happy to have her represent DDS on the committee.

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**Next Topic:** Recap of 02/13/2025 Commission Meeting

After the announcements, Dr. Benson introduced Dr. Emily Lauer from CDDER from UMass Chan Medical School to provide a recap of what was talked about during the last Commission meeting held on February 13<sup>th</sup>, 2025. Dr. Lauer's recap included that Commissioners reviewed the purpose and history of the Commission, the audience of the summary report that the Commission is charged to deliver in June of 2025, and discussed its creation, writing style, and language use, including plain language and how to address people with disabilities in the report. The rest of the meeting focused on different areas of focus and potential recommendations for the summary report.

**Vote 1:** Dr. Benson requested a motion to approve the minutes from the Commission's last meeting on February 13<sup>th</sup>, 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).

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**Next Topic:** Commission Roles - Vice Chair

Kate mentioned that the Commission voted to approve the role of vice chair in November 2025, but the position is still vacant and needs to be filled. She explained that the vice chair could assist the co-chairs in the event that either one of them or both are unavailable and by outreaching to Commissioners prior to Commission meetings to ensure attendance. She opened the floor for discussion and invited members to volunteer for the role.

**Discussion:** Mr. Green asked Dr. Benson how much time the Commission has left, and Dr. Benson confirmed three to five more full Commission meetings in the next three months. Mr. Green stated he would consider taking on this role considering it is short-term. However, he did mention he was unsure how this would implicate the role of secretary, which he is currently assigned to. Dr. Benson acknowledged Mr. Green's expressed interest and asked the Commissioners one more time if anyone else was interested; no one responded.

**Vote 1:** Dr. Benson requested a motion to install Mr. Green as the Commission's vice chair. Mr. Henning introduced the motion, which was seconded by Mr. Reggie Clark and approved by roll-call vote (see record of votes above).

**Next Topic:** Upcoming Commission Meetings

Dr. Benson discussed the upcoming end of temporary open meeting law rules allowing virtual meetings on March 31, 2025, and the uncertainty about future allowances for virtual or hybrid meetings for the Commission. She also mentioned the need to adjust plans for the next meeting

based on this decision. Additionally, she addressed scheduling conflicts for the April 10<sup>th</sup> meeting, emphasizing the need for nine members to make quorum and asking who would be unavailable.

**Discussion:**

- Ms. Fracht confirmed her attendance for the April 10<sup>th</sup> meeting.
- Mr. Green asked if this meant that after March 31st, the Commission would have to meet in person instead of online unless the rules change before the end of the month?
  - Dr. Lauer confirmed that the ability to meet online for open meetings is temporary and may end soon, with discussions ongoing about extending the temporary rule. This change will affect all commissions in Massachusetts.
- Mr. Samuel Edwards asked where the Commission would meet if in-person meetings are required and if there is there a chance the Commission could get an exception for a hybrid option due to the nature of the Commission’s work and accessibility concerns.
  - Dr. Benson confirmed that an exception could be granted.
- Mr. Clark expressed concern about not having transportation to attend in-person meetings due to limited access to transportation.
  - Dr. Benson acknowledged that accessibility and transportation are significant issues for some Commissioners, especially since one of the co-chairs lives in a remote area.
- Mr. Henning believes that the Massachusetts General Court will likely continue allowing virtual meetings, despite opposition from some groups. He notes that many legislators prefer virtual meetings, and that state government has embraced remote work more than private businesses.
  - Dr. Benson agreed, highlighting that virtual meetings have significantly improved Commission-related participation. Both hope that the virtual meeting option will remain available.
- Mr. Green suggested planning a later meeting date as a backup in case the virtual meeting rules are not extended immediately. He offered to drive Mr. Clark if given a few weeks' notice. Mr. Green also emphasized the importance of planning in advance to accommodate everyone's needs.
  - Dr. Benson stated she could attend an in-person meeting if scheduled later in April.
- Dr. Lauer mentioned that there are rules allowing remote participation as an accommodation, which they need to explore further. One option is to hold a physical meeting but allow remote participation by exception. She suggested taking a vote to hold the next meeting remotely, similar to what local disability commissions do.

**Vote 3:** Dr. Benson agreed and asked for a motion to hold the next Commission meeting virtually to ensure access for everyone. Ms. Fracht introduced the motion, which was seconded by Mr. Reggie Clark and approved by roll-call vote (see record of votes above).

**Next Topic:** Proposed Recommendations for the Framework for Remembrance

**Recommendation Review & Approval Process:**

Dr. Benson outlined a proposed process for discussing recommendations for the Framework for Remembrance identified by the working group. Each recommendation will be presented, followed by a discussion. The commission will then vote to include the recommendation in the final report or send it back to the working group for revisions if needed.

## **Recommendation #1 – Disability History Museum**

Dr. Benson introduced the first recommendation to create a disability history museum. This museum would preserve the history of residents from state institutions, highlight the independent living movement, and support ongoing integration efforts. It would also serve as a resource hub for former patients and their families. The goal is to make it accessible to everyone, whether as a physical or digital space. She then opened the floor for discussion.

### **Discussion:**

- Mr. Henning expressed strong support for the idea of a disability history museum, noting its ambition and importance in preserving history and highlighting the ongoing disability rights movement. He suggested starting with digital resources, which could eventually lead to a physical museum. Mr. Henning also shared an anecdote about a powerful temporary exhibit on disability rights at the Smithsonian, emphasizing the impact such a museum could have. Mr. Henning later reinforced his preference of physical experiences but acknowledged the importance of digital mediums. He mentioned an upcoming PBS American Experience feature, *Change, Not Charity: The Americans with Disabilities Act*, that uses digital archives, highlighting the practical application and broad audience reach of digital content. He supports using both physical and digital methods.
- Mr. Green appreciated Mr. Henning's points about preserving historical institutions and is undecided about whether to focus on physical or digital methods. He sees benefits in both approaches, especially in teaching, and is interested in hearing opinions from other Commissioners.
- Mr. Edwards expressed that he sees advantages and disadvantages in both physical and digital spaces, noting accessibility varies for different people. He raised a concern about how museums and archives would collaborate, especially regarding the display of certain records, and emphasized the importance of communication between museum and archive staff.
- Mr. Vesper Moore Vesper agreed with Mr. Edwards about the benefits of both physical and digital spaces. He mentioned that creating a large museum can take up to 35 years due to specific requirements for artifacts. He suggested a historical gallery as a quicker alternative and emphasized the need for a digital element for success.
- Mr. Green suggested that the report should address the practical steps needed to implement the recommendation, emphasizing the importance of involving the right people early on. He asked Commissioners for recommendations on the initial steps to take on this recommendation.
  - Dr. Benson agreed, recommending feasibility studies as the first step, based on her experience with school and museum properties. She believes that once a group is formed and the direction is clear, the actual first step can be identified.
- Dr. Benson questioned whether the term "museum" is appropriate for their project, suggesting it might be more of an education hub or network. She raised concerns about "museuming" individuals with disabilities and prefers a focus on advocacy and the future.
  - Mr. Moore agreed, noting that educational centers keep things active and contemporary, citing the Ed Roberts Campus in Berkley, California as an example. He discussed possibly creating something similar on the east coast, leveraging historical institutions in Massachusetts.

- Mr. Green proposed drafting simple bill language to include in the summary report's appendix, suggesting it could help with funding or legislative action.
  - Mr. Edwards agreed, emphasizing the importance of a feasibility study and involving various stakeholders. He raised concerns about the logistics and preservation issues of moving records between archives and a museum.
  - Mr. Green asked Mr. Edwards to review any draft bill language Mr. Green writes for the feasibility study by including necessary stakeholders in order for this recommendation to happen.
  - Mr. Edwards suggested a digital repository, similar to the digital transgender archive, as a more feasible option than a physical museum, highlighting the complexities of preservation and stakeholder involvement.
- Dr. Benson suggested creating a roadmap or outline to guide the planning process, including representatives from various fields.
  - Mr. Green agreed and proposed consulting a Smithsonian expert on digital and physical exhibits for recommendations.
  - Mr. Moore offered to reach out to his contact expert for further guidance.

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

### **Recommendation #2 – Perpetual Care Fund**

Dr. Benson introduced the second recommendation of a perpetual care fund to support the ongoing maintenance of cemeteries and provide grants for memorials. She emphasized the urgency of establishing this fund as those currently memorializing cemeteries are nearing retirement, highlighting the need to ensure the cemetery care continues for future generations.

#### **Discussion:**

- Mr. Green mentioned a previous draft of bill language for a similar fund, highlighting the importance of having a foundation for the proposal.

### **Recommendation #3 – Day of Remembrance Proclamation**

Dr. Benson introduced the third recommendation of a statewide day of remembrance to honor those who lived in Massachusetts state institutions, highlighting their importance in the state's history. The purpose of this annual event would help reduce stigma around disabilities, raise awareness, and educate the community about inclusion and accessibility efforts. To make it official, they would request a proclamation from Governor Healey.

#### **Discussion:**

- Mr. Moore suggested aligning the day of remembrance with Disability Pride Month or another relevant observance.
  - Dr. Benson agreed, noting the importance of giving this piece of history extra attention.
- Mr. Henning expressed mixed views on this recommendation, supporting it only if it doesn't overshadow other important initiatives requiring legislative changes or funding. He shared concerns that state officials might opt for an easy solution, like a ceremony, instead of addressing more substantial and immediate issues.

- Dr. Benson agreed, acknowledging the importance of timing and context to ensure the initiative doesn't detract from other efforts. They both emphasized the need for careful planning to avoid merely receiving a proclamation without meaningful action.
- Ms. Jennifer Fuglestad added that she found that California's annual Day of Remembrance is tied to the date the bill for the California Memorial Project was signed. This day in September also commemorates the bill that funded cemetery restoration.
- Mr. Green expressed skepticism about Days of Remembrance, agreeing with Mr. Henning's concerns that they can sometimes avoid addressing more difficult issues. He emphasized the importance of meaningful action over symbolic gestures.

#### **Recommendation #4 – Formal Apology**

Dr. Benson introduced the fourth and final recommendation of a formal apology from the State of Massachusetts for the neglect of state-run cemeteries and the harm caused by state institutions. This apology would acknowledge past mistreatment and emphasize accountability, while committing to educating the public about the history of state institutions for people with disabilities. She cited examples from Georgia and Minnesota, where similar apologies were issued, and invited discussion on the recommendation. The Georgia Department of Mental Health apologized for neglecting cemeteries and harming patients, while Minnesota's legislature passed a resolution in 2009 apologizing for the harm caused by institutionalization.

#### **Discussion:**

- Mr. Moore supported issuing an apology, noting that many organizations have done so in the past, including the American Psychiatric Association in 2018 for its role in ongoing racism. He emphasized the importance of acknowledging past wrongs and moving forward, especially in archiving and celebrating people with disabilities.
- Mr. Green liked the language of the Minnesota bill, noting its thoughtful and respectful approach to acknowledging past harms. He highlighted the importance of specific details in the bill, such as the forced labor and difficult situations faced by patients. Mr. Green emphasized that the apology should come from the governor of Massachusetts, as it would carry more weight and historical significance. He also mentioned the historical involvement of Massachusetts governors in institutional policies, suggesting that a modern governor should continue this legacy by acknowledging past wrongs. Mr. Green believes this approach would be more impactful than an apology from other state officials.
- Mr. Henning expressed that he thinks public apologies for past wrongs are important because they help stop denial and prevent repeating mistakes. He mentioned that Korea is still upset with Japan for not apologizing for wartime actions.
  - Dr. Benson agreed and said Massachusetts should also make these apologies to avoid going back to old, harmful practices. She believes public apologies could help guide discussions and stop regression.
- Mr. Moore believes that a formal apology would show Massachusetts' commitment to the disability community and behavioral health initiatives. He also mentioned that the Olmstead decision, which supports living in the community rather than institutions, could be referenced in the public apology.

- Dr. Benson agreed, adding that since Massachusetts was a pioneer in creating these institutions, it should also lead in acknowledging the negative impacts of institutionalization.
  - Mr. Green raised the point that a public apology might be hard for people unfamiliar with the topic to understand at first. He emphasized the importance of records, like those related to cemeteries, and suggested using Minnesota as an example. Mr. Green also wanted to know if it was okay to include records preservation and access, as mentioned in reports and interviews by CDDER, to the public apology.
  - Mr. Edwards thought that remembrance days would be more meaningful if they came from the disability community instead of the state. He worried these days might just be symbolic without real action.
    - Dr. Benson agreed, saying grassroots movements have been key in disability history and it's important to avoid just checking a box.
  - Mr. Clark expressed confusion about the Commission's direction, emphasizing the need to focus on local issues rather than external ones. He highlighted concerns about the mayor's lack of engagement with the disability community. Mr. Clark also stressed the need for security for any projects they undertake and the importance of direct conversations with those affected by these issues.
    - Dr. Benson agreed and noted the importance of addressing these concerns in their recommendations in the summary report.
  - There appeared to be total agreement from the commissioners, and no one spoke in opposition to the idea.
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**Next Topic:** Additional Questions and Comments

**Discussion:** Before adjourning the meeting, Dr. Benson asked if anyone had additional comments on the remembrance framework recommendations. She also reminded everyone that the special commission email was open for suggestions. She thanked everyone for the discussion and mentioned the next full commission meeting in April and that CDDER would follow up with meeting details and information about open meeting law changes.

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**Next Topic:** Adjourn Meeting

**Vote 4:** Dr. Benson asked if there was a motion to adjourn. Mr. Clark introduced the motion, which was seconded by Mr. Green and approved by roll-call vote (see record of votes above).

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**Meeting Materials:**

1. SCSJ meeting presentation
2. SCSJ meeting minutes from February 13, 2025
3. Speech by Thomas Hester
4. Minnesota House File 1680
5. [Minnesota finally apologizes to thousands of mentally disabled](#)- MinnPost Article