

## Special Commission on State Institutions

### Meeting Minutes

July 18, 2024

3:00 PM - 4:30 PM

Date of meeting: Thursday, July 18, 2024

Start time: 3:06PM

End time: 4:39PM

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1*	Vote 2	Vote 3
<b>Evelyn Mateo (co-chair)</b> – Department of Mental Health (DMH)	X	X	X
<b>Matthew Millett (co-chair)</b> – Department of Developmental Services (DDS)	-	-	-
<b>Elise Aronne</b> – Wrentham Developmental Center	X	X	-
<b>Kate Benson</b> – DMH designee	X	X	X
<b>Sister Linda Bessom</b> – Hogan Developmental Center family member	X	X	X
<b>Reggie Clark</b> – Massachusetts Advocates Standing Strong (MASS)	X	X	X
<b>Anne Fracht</b> – DDS designee	X	X	-
<b>Alex Green</b> – The Arc of Massachusetts designee	A	X	-
<b>Bill Henning-BCIL</b>	A	X	X
<b>Rania Kelly</b> – MassFamilies	X	X	X
<b>Andrew Levrault</b> – Disabled Persons Protection Commission (DPPC)	X	X	X
<b>Mary Mahon McCauley</b> – Massachusetts Office on Disability (MOD)	-	X	X
<b>Vesper Moore</b> – Kiva Centers	-	-	-
<b>Brenda Rankin</b> – Wrentham Developmental Center	X	X	-
<b>Conor Snow</b> – Secretary of State, Archives Division	X	X	X

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

### Proceedings

Ms. Mateo, Commission Co-chair, called the meeting of the Special Commission on State Institutions to order at 3:06 PM. She welcomed members and reminded them that full Commission meetings are subject to Open Meeting Law and any votes taken are conducted via rollcall. 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. Lastly, she said that CDDER would review any questions from the audience and would wait to answer them towards the end of the meeting.

After reviewing the meeting “housekeeping” items, Ms. Mateo introduced the Commission’s newest member, Bill Henning, Director of the Boston Center for Independent Living, as well as announced the departure of another member, Conor Snow, the Massachusetts State Archives representative. Both individuals were given the opportunity to share some words with the Commission.

Next, Ms. Mateo 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 in May 2024. Dr. Lauer’s recap included the following:

1. A tool of commonly used terms and acronyms prepared by CDDER.

2. A proposed timeline for the Commission's work, including a draft report due in September, which covers the topics of burials, records, and a memorial.
3. Additional meetings scheduled in the fall to provide the Commission enough time to review all report topics.
4. Recent media relevant to the work of the Commission, including the planning process for the Fernald grounds, a family member's efforts to get records about their family member who lived at Fernald, and confidential police files that were not properly or securely stored at Fernald.
5. Work group updates were also provided:
  - Records and record access: Commissioners discussed a state bill that was proposed in the past that would give people access to public records from institutions, the idea of an amnesty program to incentivize people to return previously stolen, sold, or purchased items from institutions without facing criminal charges, and information gathered from 36 other states about their record access rules.
  - Burial and burial locations: The group talked about creating a list of all known institutional cemeteries in the state and using a gap analysis tool to review the status of them. They also talked about the need to educate local towns and city officials about how to properly search for unmarked graves and what to do when there is a suspected unmarked grave in their town.
  - Framework for public recognition: The group talked about what they learned from the presentation delivered by the Willowbrook New York memorial committee.

**Vote 1 to approve the 03/21/2024 meeting minutes:** Ms. Mateo requested a motion to approve the minutes from the Commission's last meeting on May 30, 2024. Mr. Andrew Levrault introduced the motion, which was seconded by Ms. Rania Kelly and approved by roll-call vote (see record of votes above).

**Next topic of discussion:** Letter of Inquiry

CDDER provided a summary of the responses to the five requests that were included in the letter of inquiry that the Commission sent to the Governor and the Secretary of Health and Human Services.

1. Search for records left behind in closed institutions: The Department of Mental Health (DMH) and the Department of Developmental Services (DDS) reported that all records were moved to another facility before the closure and change of ownership of any institution. It was also reported that the buildings of some of the closed institutions are not safe to enter and search. The Executive Offices of Health and Human Services (EOHHS) are going to survey these properties.
2. Address record-related security issues: EOHHS said they did not find any security issues related to records, except for the issues discovered at Fernald. Any security issues that arise will be addressed quickly following federal and state laws.
3. Make the records request process easier: EOHHS is working on making this process easier for former institutional residents and their families. The current process to request records can be found on the DDS and DMH websites. Currently, state law allows families to get access to medical records of their family members from DDS and DMH under certain conditions, e.g., if they are legally authorized to represent their family member, if there is a

court order and the client agrees, or if the commissioner decides it's best for the person to have access to their records.

4. Create process on storing and destroying confidential records: EOHSS stated that DMH and DDS both have a privacy handbook that explains the rules for how each agency handles and stores records that have protected health information (PHI) and that both agencies follow the Massachusetts statewide records retention schedule for deciding how long to keep records and how to dispose of them. The law that governs how long medical records must be kept requires a 20-year retention period. Medical records cannot be destroyed or moved to the State Archives unless the Records Conservation Board, which is overseen by the Secretary of the Commonwealth, gives permission. Lastly, the response letter stated a tracking system is used to monitor when records are moved, who takes them, and where they are kept.
5. Provide a list of records that may be stored at open facilities or government offices: The response letter states that both DMH and DDS maintain a list of records and have access to records still in their possession, including those stored in the State Archives.

After this summary was provided, Commissioners had the opportunity to discuss their reactions to the response letter.

- Mr. Alex Green thought the response was very general and focused mainly on Fernald. He also questioned the accuracy of the state's record tracking system because during one of the very first Commission meetings last year, the DMH representative at that time admitted that lots of records were left in buildings that were no longer being used by DMH, and that staff often admitted that they did not know what to do with them. As a result, Mr. Green would like to know how the records tracking system has changed over the past year and recommends that no records be destroyed until the process is updated and transparent. Mr. Green also talked about the experience of an individual he recently helped to get access to the records of their family member who was a former institutional resident. He stated that the agency failed to explain why most of the records were blacked out and the state should be more sensitive to situations like this and provide greater clarity when giving records to individuals and/or family members.
- DDS Deputy Assistant Commissioner, Victor Hernandez, expanded on this topic by discussing the fact that the records left behind were discovered by trespassers and that any known trespassers of any active DDS facilities should be reported directly to him, so DDS can take necessary action, including notifying local authorities.
- Jay Tallman, DMH Policy Director, agreed with Mr. Alex Green that the records access process should be easier, and more efficient and transparent. He also stated that DMH is open to any feedback and recommendations and is willing to work collaboratively with the Commission to improve the records access process.

**Vote 2 to take the response letter into the records access workgroup for consideration and recommendations for next steps, to the chairs, before the next meeting:** Mr. Bill Henning commented that it seems that there is further action needed to be taken by the Commission given the general dissatisfaction of the response letter. In response to this, Mr. Alex Green proposed and introduced a motion to take the response letter to the workgroups for consideration and recommendations for next steps, to the chairs, before the next full Commission meeting scheduled

for September 12, 2024. Ms. Mary Mahon McCauley agreed with Mr. Green's proposal and seconded the motion, which was approved by rollcall (see records of votes above).

**Next topic of discussion:** Recent Developments

Ms. Mateo discussed a WGBH news article that was published since the last full Commission meeting about ongoing vandalism of the Fernald property and the discovery of the Nazi/skin head graffiti. Commissioners then had the opportunity to discuss their reactions to the article.

- Mr. Green felt the article was very disturbing and shared his disbelief with respect to the City of Waltham's response to the discovery and that the city did not consider it to be a hate crime. Ms. Mary Mahon McCauley also found the findings at Fernald extremely disturbing.

**Next topic of discussion:** Update from Workgroups

Ms. Mateo stated that the workgroups are still looking for additional members and that Commissioners can sign up to any workgroup by emailing the SCSI Support email address. Next, she invited each workgroup to provide an update.

- **Records and Records Access Workgroup:**

Mr. Green provided the following updates on this workgroup:

- There is a bill in the Senate (S1965) and in the House (H3033) that will release records after 75 years of being held in the Massachusetts State Archives. Although highly unlikely, the bill can pass at the end of July through the legislative formal session or through an "informal session."
- DDS is currently processing records requests from family members of former DDS institutional residents.
- With the support of CDDER, the Workgroup is currently working with DMH to get access to Foxboro State Hospital records with the purpose of recreating a list of people buried on hospital grounds.

- **Burials and Burial Locations Workgroup:**

Ms. Kate Benson provided the following updates on this workgroup:

- The workgroup has compiled a list of 26 known burial locations of former institutional residents, including cemeteries located on the grounds of former institutions or burial plots found in town cemeteries.
- As shared before, the workgroup has created a gap analysis tool to help evaluate the state of each of these known burial locations, including, but not limited to whether cemeteries are maintained, if they have marked or unmarked graves, if there has been vandalism, and if there is some type of memorial. An example of a gap analysis of the Northampton State Hospital cemetery was presented.
  - The workgroup has requested assistance from the Massachusetts' State Archaeologist's Office for guidance on what steps to take if an unmarked grave is suspected at any of the sites of former institutions.
  - The workgroup would like to know how the Commission would like to:
    - Complete the gap analysis for each cemetery?
    - Explore the likelihood and possible locations of unmarked graves?
    - Address the issue of "lost cemeteries"?

- Dr. Lauer explained that CDDER has started the gap analysis of the known cemeteries to date through paper and online record review. However, she expressed that there is more work to be done and that the Commission may consider increasing its budget to complete the gap analysis, giving recommendations in its final report on how this work should be done going forward, and/or requesting some additional assistance.
- **Framework for Remembrance Workgroup:**  
Mr. Reggie Clark and Ms. Jennifer Fuglestad (from CDDER) provided the following updates on this workgroup:
  - The Willowbrook Mile steering committee delivered a presentation to the workgroup in June 2024. Some of the takeaways included that the memorial, the Willowbrook Mile, is dedicated to only one institution, which is the Willowbrook State School on Staten Island in New York. The project also took several years to complete and included gathering input from various stakeholders, securing local legislature support (funding and the property), conducting ongoing fundraising, and designing the memorial itself.
  - CDDER is scheduled to meet with a group of people from the California Department of State Hospitals that created the California Memorial Project to learn more about their strategies on developing a statewide framework for remembrance.

**Next topic of discussion: History of Massachusetts Institutions**

Ms. Fuglestad delivered a short presentation on the historical timeline of institutions in Massachusetts with the goal of defining the research scope of the Commission.

- Institutional Care for the Poor (colonial times to early 1800's)
  - The concept of institutions and formal institutional care was developed to take care of the poor. These institutions were called almshouses, and a large percentage of its poor population had a mental illness and/or developmental disability.
- Institutional Care for People with Disabilities (1830's - 1860's)
  - The state created asylums to provide better care for poor adults with mental illness and/or a developmental disability. They also created special schools for children who were poor (primary school) and others for children involved in the court system (e.g., reform, industrial, and training schools).
  - The creation of the Training School for the Blind (Perkins) and the School for Idiotic and Feeble-minded Youth (Fernald) was a result of schools struggling with what to do with "feeble-minded" children.
- Expansion of Institutional Care for People with Disabilities (Late 1880's - Early 1930's)
  - Approximately 15 institutions for the insane and the feeble-minded were built across the state.
    - People with disabilities were grouped and isolated so they would not be mixed with regular society or reproduce (population control via eugenics).
    - The IQ test was used to screen and categorize people, including the poor, immigrants, and children.
- Defective Delinquents (early 1900's)

- The state conducted a study because of a rise in crime and individuals labeled as "mentally ill" or "mentally deficient." These people were considered to be mentally deficient criminals and were formally called "defective delinquents."
- As a result of this, the legislature authorized the segregation of these individuals by establishing the Department of Defective Delinquents, which allowed for the permanent removal of these people from society and placement into custodial care for the rest of their lives.
- Wardens of prisons, and superintendents of asylums for the insane and schools for the feeble-minded had the authority to transfer anyone they served to the Department of Defective Delinquents if they thought that person was not suitable for their institution.
- History Summary
  - People with mental illnesses and developmental disabilities were included in many different types of institutional settings in Massachusetts over time, including, but not limited to almshouses, asylums, hospitals, special reform and training schools for children, as well as prisons and the Department of Defective Delinquents.

Commissioners then had the opportunity to discuss the scope of the Commission's research based on the presentation of the history of institutions in Massachusetts.

- Ms. Benson believes the Commission needs to start thinking about how it will incorporate some of the earlier institutions into its research.
- Mr. Henning was appreciative of the presentation and considered it to be critical background for the scope of our research and how people were wrongfully segregated and punished.
- Mr. Andrew Levrault suggested starting our research with currently operating and most recently closed institutions and then working our way backwards.
- Sister Linda Besom suggested that there be some type of public apology given the inhumane treatment that occurred in these institutions.
- Mr. Green supported Sister Besom's contribution and stated that her thinking was aligned with what Senator Barret wanted from the Commission, which was to think expansively, radically, and progressively about the aim and goals of the Commission. He also encouraged her to join the Framework for Remembrance Workgroup given her work with other public apologies around the trans-Atlantic slave trade.
- Ms. Mahon McCauley agreed with Mr. Levrault's suggestion and added that the Commission should just focus on the institutions that were created specifically for people with mental illness and intellectual developmental disabilities, the research should be broken down by decade, and should focus on the institutions that were closed in the past 50 years.

**Vote 3: Adjourn meeting:** Ms. Mateo reminded everyone about the next full Commission meeting scheduled for September 12<sup>th</sup>, 2024, from 2:30PM to 4:30PM. Thereafter, Mr. Henning entered a motion to adjourn the meeting at 4:39PM, Ms. Mahon McCauley seconded the motion (see records of votes above).

#### Meeting Materials

1. SCSJ presentation