

Special Commission on State Institutions

Meeting Minutes

March 21, 2024

3:00 - 4:30 pm

Date of meeting: Thursday, March 21, 2024

Start time: 3:05pm

End time: 4:15 pm

Location: Virtual Meeting (Zoom)

Member Name / Seat	Vote 1*	Vote 2	Vote 3	Vote 4
Evelyn Mateo (co-chair) – Department of Mental Health (DMH)	X	X	X	X
Matthew Millett (co-chair) – Department of Developmental Services (DDS)	X	X	X	X
Elise Aronne – Wrentham Developmental Center	“Hi”	X	X	-
Kate Benson – DMH designee	X	X	X	X
Sr Linda Bessom – Hogan Developmental Center family member	A	X	A	X
Reggie Clark – Massachusetts Advocates Standing Strong (MASS)	X	X	X	X
Anne Fracht – DDS designee	-	X	X	X
Alex Green – The Arc of Massachusetts designee	X	X	X	X
Rania Kelly – MassFamilies	X	X	X	X
Andrew Levrault – Disabled Persons Protection Commission (DPPC)	X	X	Present	X
Julia O’Leary – Massachusetts Office on Disability (MOD)	A	X	A	X
Vesper Moore – Kiva Centers	X	X	X	X
Brenda Rankin – Wrentham Developmental Center	X	X	X	-
Conor Snow – Secretary of State, Archives Division	-	X	X	X
Mary-Louise White – DMH	-	-	-	-

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

Proceedings

Mr. Millett, Commission Co-chair, called the meeting of the Special Commission on State Institutions to order at 3:05 pm. He told the group that his co-chair Evelyn Mateo should be joining the meeting shortly, which she did at 3:06PM. He reminded members that the meeting must follow the Open Meeting Law. He told Commissioners that CART services were available during the meeting. He also told Commissioners that meeting notes would be made available and that the meeting was going to be recorded.

Evelyn introduced a new Commission member, Sister Linda Bessom, who is a family member and guardian of a current resident of the Hogan Developmental Center. She also introduced Julia O’Leary from the Massachusetts Office on Disability (MOD) who was attending the meeting for Mary Mahon McCauley.

Vote 1 to approve the 01/18/2024 meeting minutes: Mr. Millett requested a motion to approve the minutes from the Commission's previous meeting on January 18, 2024. Mr. Alex Green introduced the motion, which was seconded by Ms. Anne Fracht and approved by roll-call vote (see record of votes above). Reminder that the Commission's meeting materials are available on the Commission's webpage.

Mr. Millett 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. Dr. Lauer's recap included the following:

- The CDDER Team was introduced to the Commission and their role in supporting the Commission's work was discussed. As a result, Commissioners agreed to form 3 working groups that focus on the areas identified below:
 1. Goals 1 and 2: Existing records and request process
 2. Goals 3 and 4: Burial locations
 3. Goal 5: Framework for public recognition
- Commissioners and CDDER discussed the Boston Globe article that was about important papers left behind at Fernald after it closed, including papers that had details about people who lived there and their health. The Commission voted to draft a Letter of Inquiry about how this happened and what will happen going forward.
- CDDER shared with the Commission members what they have learned so far in each of the three areas of focus. The need to define "institution" for the purposes of this work was also discussed in order to clarify what will be included and what will not. CDDER also discussed some of the next things they plan to do and got input from the Commissioners on these steps.

Next topic of discussion: Presentation of draft commission Power Point templates and YouTube channel update

- **Power Point template samples**
 - Commissioners wanted to see how they might brand the Commission different than the state's generic template that has been used for PowerPoints during past Commission meetings. In response to this, Christine Roa from CDDER presented 3 PowerPoint template designs for the Commission to discuss and possibly choose from. Most of the Commissioners liked the light red, white, and blue design.

Vote 2 to approve the light red, white, and blue PowerPoint template design: Mr. Millett asked if any Commissioner would like to make a motion to formally vote on the design. Mr. Vesper Moore introduced the motion, which was seconded by Ms. Kate Benson and approved by roll-call vote (see record of votes above). The template will be used in future meetings.

- **YouTube channel update**
 - CDDER has created a YouTube channel for the Commission. All videos previously hosted on MOD's YouTube channel have been moved over to the Commission's YouTube

channel. All full Commission meetings that have been recorded can be found on the Commission's website or on the commission's YouTube channel.

Next topic of discussion: Recent Boston Globe articles and news coverage on developments regarding Bridgewater State Hospital, Tewksbury State Hospital, and Fernald State School

Ms. Mateo provided a short summary of the news articles and media coverage on these state hospitals and schools.

- **Bridgewater State Hospital**

- The article stated that the Disability Law Center recently released a report about the lack of progress for improvements at Bridgewater State Hospital. The report recommended that the facility be run by the Department of Mental Health and not by the Department of Corrections.
 - Mr. Green explained that Bridgewater State Hospital is a jail that used to take patients who were at state schools like Fernald a long time ago. He stated that because of these details, any work done by the Commission on Bridgewater State would likely be different. He also mentioned that it will be important to define what an institution is, especially for facilities like Bridgewater that provided services to other populations.

- **Tewksbury State Hospital**

- The article stated that conditions at Tewksbury State Hospital are being affected by the number of patients that have been transferred from Bridgewater State Hospital. Tewksbury is another state hospital that has a section for people with mental health conditions.

- **Fernald State School**

- There was an article in the Boston Globe at the end of February that discussed the desire of the people who lived and worked at Fernald to have a say in what should happen to the grounds as it was redeveloped.
- There was an editorial written by the Globe Editorial board published in the Boston Globe on January 30th as a follow up to the January 10th article that talked about the City of Waltham letting the buildings on the former grounds of the Fernald State School to fall into disrepair due to neglect.
- There was a radio interview on WGBH regarding access to records of former residents of state schools by family members.
 - Mr. Clark, who was quoted and interviewed by WGBH, shared how he feels that the people who lived at these former state schools and their families should be the only ones to decide what should happen to these records. He also suggested creating something like a museum to show the history of the people that used to live at Fernald.

Next topic of discussion: DDS Health Insurance Portability and Accountability Act (HIPAA) breach notice

Dr. Emily Lauer summarized the recent DDS press release and the information on the DDS website about the HIPAA breach.

- On March 11th, DDS released a HIPAA breach notice. This notice is required by HIPAA when a group learns that personal health information has not been protected as required by this law.
- DDS confirmed the records that were not secured had names, dates of birth, diagnoses, medical information, medication/prescription information, and other treatment information. They may have also had social security numbers.
- The notice said that DDS does not know of any times this information was used in ways it should not be.
- It said people who lived at Fernald should watch their bank accounts for any charges they do not recognize and call their bank if they see anything like this.
- DDS also gave out a toll-free assistance line for questions and an email address and mailing address for their privacy officer. They also shared a website with information.

Victor Hernandez, DDS Deputy Assistant Commissioner, provided more updates on the HIPAA breach notice and the records that were found on the grounds of the former Fernald State School.

- In January, DDS was notified that patient and staff records were found in some of the buildings located on the grounds of the former Fernald State School. DDS responded to this news by asking the city of Waltham if they could go inside any buildings that were safe enough so that they could collect as many of these records as possible. Since the conditions of most of these records were not safe, DDS had to hire a professional company to do the clean-up, which was done on March 7th. The records that were collected are now safely secured at a DDS facility.
- Since rules for HIPAA were not followed, DDS made a public announcement on its website and through a press release letting the public know about the records that were found at Fernald.
- In addition to making a public announcement, DDS is currently working with the State Archivist and the Secretary of State's office to get their recommendations on what they should do with the records and what they must do to keep them.

Next topic of discussion: Update from Workgroups

Mr. Millett 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.

- **Workgroup 1: Letter of Inquiry**

Mr. Clark provided an update on this workgroup.

- The workgroup identified and included the following requests in the letter, which is addressed to Governor Healey and the Secretary of Health:
 - Find any records that may still be located at any closed DDS and DMH institutions.
 - Resolve any security issues that are identified during the search for old records.
 - Make the process to request records easier for former patients and family members.
 - Create a clear process for how personal records are stored and when they can be destroyed.
 - Provide a list of records that may be stored at facilities or any of the government offices that are still in operation.
 - The letter also requested a response to the letter within 90 days.

Mr. Alex Green expressed that he appreciates what DDS has done and shared so far with the public about these records. He also stated he would like DMH to report on what the agency has been doing on this same topic. He noted that the Commissioner that represents DMH has not participated in a full Commission meeting in a while and that their representation is important to the work of the Commission.

Vote 3 for the Commission to approve the letter of inquiry on the Boston Globe articles. Mr. Millett requested a motion to approve the letter of inquiry. Ms. Kate Benson introduced the motion, which was seconded by Ms. Anne Fracht and approved by roll-call vote (see record of votes above). The letter will be sent out sometime before the end of March.

- **Workgroup 2: Records and Record Access**
 - Mr. Alex Green gave an update of what the workgroup has done so far. He stated the workgroup has met twice since that last full Commission meeting.
 - During these meetings, the workgroup has discussed different legal views of the public record law, current legislative activity about this law, and the possibility of partnering with local law schools for free assistance with the researching of records.
 - The workgroup's next steps are to include the mapping out of the state record retention guidelines and to do interviews with the state's Supervisor of Records, Division of Open Government, and people who have tried to get records.
- **Workgroup 3: Burial and Burial Locations**
 - Ms. Kate Benson gave an update of what the workgroup has done so far.
 - The workgroup has discussed the status of existing cemeteries and burial locations that are formally taken care of or not.
 - The workgroup's next steps are to create a gap analysis of existing cemeteries in order to identify what cemeteries may be missing in comparison to a cemetery that is well maintained, request burial practices from institutions that have cemeteries that are still in use, and to continue doing interviews to find out more information about this topic.
 - A gap analysis is when you analyze the current state of something and compare it to where it should be or where you want it to be.
- **Workgroup 4: Framework for Public Recognition**

- Ms. Rania Kelly gave an update of what the workgroup has done so far.
- The workgroup has discussed the vision and mission and goal of the remembrance, examples of how other states, including Massachusetts, have remembered people who lived in these types of institutions, and the possibility of partnering with architecture or design programs from local universities to help develop the public recognition.
- The workgroup's next step is to meet with Belchertown State School Friends Association in April to get an understanding of what this group had to go through in order to create a memorial in honor of former patients from the Belchertown State School.

Mr. Millett thanked everyone for their participation today. He also reminded everyone that the next 2 Commission meetings will take place on Thursday, May 30th at 3:00PM and on Thursday, July 18th at 3:00PM.

In response to this, Victor Hernandez, DDS Deputy Assistant Commissioner, notified the group that DDS will be holding a remembrance celebration at the Belchertown State School cemetery and at the Monson State School cemetery in late May. Once he has the invitation, he will send it to CDDER so they can forward it to the Commissioners.

Vote 4: Adjourn meeting: Mr. Clark entered a motion to adjourn the meeting at 4:15pm, Ms. Kelly seconded the motion.

Meeting Materials

1. SCSJ presentation