

# Special Commission on State Institutions

December 12, 2024

3:00 PM – 5:00 PM

Virtual / Zoom

**Kate Benson**

**Co-chair**

**Matt Millett**

**Co-chair**

# Agenda

1. Welcome
2. Recap of last meeting
3. Vote to approve minutes from 11/14/24 meeting
4. Commission Roles and Vacant Seats
5. Upcoming Work of Special Commission
6. Summary Review of CDDER Draft Report
7. Next steps
8. Vote to adjourn

# Welcome

- ▶ Recap of Last Meeting
- ▶ Vote to approve 11/14/24 meeting minutes
- ▶ Commission Roles and Vacant Seats

# Commission Roles and Vacant Seats

- ▶ Vacant Position-Vice Chair
- ▶ Approved by vote in November SCSI Meeting
- ▶ The vice chair would be responsible for:
  - ▶ Coordinating regularly with the co-Chairs
  - ▶ Chairing meetings in the absence of one of the co-Chairs
  - ▶ Acting as Chair when requested to do so by one of the co-Chairs
  - ▶ Assisting with tasks as requested
- ▶ Vacant Commission Seat
  - ▶ Family member of a current resident of the Wrentham Developmental Center

# Upcoming Work

December 2024 to June 2025

# Upcoming Work of the Special Commission

- ▶ Upcoming Work
  - ▶ Review CDDER Report
  - ▶ Generate Recommendations
  - ▶ Write the SCSI Report- **Due June 1, 2025**

# 2025 Commission Meetings

- ▶ Frequency of Meetings
- ▶ Day and time of meetings

# Report Review Working Group

- ▶ SCSI voted to approve a Report Review Working Group
- ▶ The Purpose of working group is to collect feedback, comments and edits on the CDDER Draft Report
- ▶ Working group is looking for 2-3 additional Commission members

# Summary of Draft Report

# Warning of Use of Words

- ▶ The upcoming slides use words to describe people with disabilities that are offensive.
- ▶ The words will be shown as they were used in the past to label schools, asylums and other institutions to show the full history of institutions in the state.

# Records and Records Access: Remaining Topics

- ▶ Evolution of Governing Bodies of State Institutions
- ▶ Patient Records Examples (Past vs. Present)
- ▶ MA Public Records Law & Related Governing Bodies
- ▶ Regulations Governing Access to Patient Records
- ▶ Record Collections Held by Secretary of the Commonwealth
- ▶ Records Held by DMH and DDS
- ▶ Private Collections of Institutional Records
- ▶ Personal Experiences
- ▶ Areas for Additional Research

# Massachusetts Commission on Mental Diseases (1916-1919)

- ▶ Chapter 285 of the Acts of 1916 eliminated the Board of Insanity and established the **Massachusetts Commission on Mental Diseases**.
  - ▶ Section 1 required all records, books, and property to be transferred.
- ▶ First annual report in 1916 highlighted importance of **scientific research** at the School for the Feeble-Minded.
- ▶ Chapter 318 of the General Acts established:
  - ▶ **Free community clinics** for people the "feeble-minded."
  - ▶ **Registry for the feeble-minded** for tracking and treatment purposes.
    - ▶ Registry not subject to public inspection, except by public officials or other people having authority over the feeble-minded person.

# Department of Mental Diseases (1920-1938)

- ▶ Chapter 350 of the General Acts of 1919 replaced the Commission on Mental Diseases with the **Department of Mental Diseases**.
- ▶ By 1920, major changes in the Massachusetts public welfare system included the consolidation of over 100 state departments to just 20.
  - ▶ The Department of Mental Diseases was not impacted by these changes.
- ▶ In 1923, two new divisions were introduced:
  - ▶ Division of Mental Hygiene
  - ▶ Division for the Feeble-minded
    - ▶ In 1926, was renamed to Division of Mental Deficiency.

# Questions/Feedback

## Evolution of Governing Bodies of State Institutions

# Type of Information Collected

## ▶ Patient Records:

- ▶ Demographic Information: Marital status, birthplace, diagnosis, number of previous commitments, and the method of commitment.
- ▶ Patient Registration Number: Each patient was assigned a unique number for record-keeping purposes.

## ▶ Annual Reports:

- ▶ Operations and expenditures: Financial details about hospital operations.
- ▶ Patient movement: Commitments, admissions, transfers, discharges, and deaths.
- ▶ Department reports: Religious services, social work, pathology, etc.
- ▶ Recommendations and requests: Proposed changes to the law and funding requests for institutional improvements and expansion.
- ▶ Mental health conditions and general health of the population.

# Record Preservation and Storage (late 1800's – early 1900's)

- ▶ MA General Law has mandated that government entities must provide fire-resistant and fireproof rooms, safes, or vaults for safeguarding public records since the late 1800's.
- ▶ Annual reports document requests for funds to comply with record storage requirements.
  - ▶ In 1916, Grafton State Hospital's Superintendent requested \$900 to create a fireproof room for storing records.
  - ▶ In 1923, the Belchertown State School's Superintendent requested funds for an administration building with a fireproof vault.

# Special Committee of Superintendents for Uniform Records (1918 – 1919)

- ▶ In 1918, a special committee of superintendents was formed to standardize record-keeping across state institutions.
- ▶ By 1919, there were several improvements in records:
  - ▶ The Boston Psychopathic Hospital - Detailed clinical histories, and it made sure that records were easy to access.
  - ▶ Worcester State Hospital - Held clinical meetings to review patient summaries, physical and mental health findings, and social service reports.
  - ▶ Grafton State Hospital - Typewritten pathology records, which were organized into volumes.
  - ▶ Boston State Hospital - Patient records were maintained chronologically, including all patient history and actions taken.

# Record-Keeping Practices (Past vs. Present)

- ▶ *A Brief History of the Taunton Lunatic Hospital 1854 - 2016* by Joseph Langlois.
  - ▶ Informal analysis of the medical records stored at Taunton State Hospital
  - ▶ Illustrated a gradual improvement in the quality and thoroughness of medical records, shifting from brief, sparse documentation to more detailed, structured records.
- ▶ Key Informant Interviews: State hospitals kept inpatient admission cards in alphabetical order by patient name and the year they were admitted and could include information about the patient's death
  - ▶ Unclear how long the records are kept or the specific periods they cover
  - ▶ Some records from Taunton and Foxborough are securely stored at Taunton State Hospital

# Questions/Feedback

## Patient Records Examples (Past vs. Present)

# MA Public Record Law

- ▶ **Right to Access:** In Massachusetts, everyone has the right to see public records held by state and local government offices. You can look at, copy, or get copies of these records for a reasonable fee.
- ▶ **Definition of Public Records:** Public records include many types of materials made or received by government offices. This can be books, papers, maps, photos, financial records, and other documents.
- ▶ **Presumption of Public Access:** Most records held by the government are open to the public unless there is a special reason not to share them. This helps people see how the government is working.

# MA Public Records Law – Some Exemptions

- ▶ Personal Identifying Information: Personal details like names, Social Security numbers or private addresses are kept private to protect people's privacy
- ▶ Juvenile Delinquency Records: These records are kept private and not available to the public
- ▶ Criminal Offender Record Information (CORI): Criminal records are not available to the public unless allowed by law
- ▶ Personnel and Medical Files: Personnel and medical records that could harm privacy are kept private
- ▶ Exemption for Institutional Records: the law specifically exempts records related to individuals from certain state institutions

# Who Oversees Public Records?

Public Records are managed under the Secretary of the Commonwealth

- ▶ Records Conservation Board (RCB):
  - ▶ Maintains the Statewide Records Retention Schedule (SRRS)
  - ▶ Agencies need RCB's permission to destroy records or to move them to the State Archives
  - ▶ Some records from closed institutions have been destroyed during times when the policy allowed it
- ▶ Supervisor of Records:
  - ▶ Decides if a government record should be made public or if it is exempt from being shared under the Public Records Law
  - ▶ Oversees the appeal process to decide if access should be granted

# Who Oversees Public Records? (Cont.)

- ▶ Records Management Unit (RMU)
  - ▶ Ensures proper storage and preservation of government records
  - ▶ Assists state agencies in managing and securing their records
  - ▶ Provides guidance on various record-keeping issues
- ▶ Records Access Officers (RAO)
  - ▶ Manage requests for records made to their agency
  - ▶ Both DDS and DMH have Records Access Officers

# Request Process for Public Records

- ▶ Requests can be made to a Records Access Officer (RAO) in person, by mail, fax, or email.
- ▶ RAO's have 10 business days to reply.
- ▶ RAO must provide an explanation if
  - ▶ They don't have certain records; or
  - ▶ They are unable to share the records.
- ▶ RAO must provide information about the requestor's Right of Appeals
  - ▶ Appeals are made to the Supervisor of Records

# Five-Minute Break

# Questions/Feedback

## MA Public Records Law & Related Governing Bodies

# Access Rules for Institutional Patient Records

## ▶ Privacy of Patient Records:

- ▶ Require records to be kept private and secure, with some exceptions:
  - ▶ Court Order
  - ▶ Legally Authorized Representatives
  - ▶ Patient or Attorney Request
  - ▶ Best Interest of the Patient
  - ▶ Where otherwise required by law

## ▶ Retention of Medical Records:

- ▶ A 20-year retention period is mandated for medical records under state law.
- ▶ Records cannot be destroyed or transferred to the MA State Archives without prior approval from the Records Conservation Board.

# Current DMH & DDS Regulations on Records

- ▶ DDS and DMH's most recent regulations on records include:
  - ▶ DDS Regulation 115 CMR 4.00 (last updated in 2009)
  - ▶ DMH Regulation 104 CMR 27.00 (last updated in 2021)
- ▶ Outline the requirements for patient records to ensure comprehensive, accessible, and accountable record-keeping for people receiving services
- ▶ Establishes quality standards for record keeping, including privacy and confidentiality of patient records.

# Record Request for Former or Current Service Recipients

- ▶ Process is outlined on the DMH and DDS webpages
  - ▶ Requests may be denied or partially redacted (blacked out) based on legal restrictions when the records include sensitive personal or medical information.
- ▶ DMH's Restrictions: Until a court order or valid Personal Representative authorization is provided, DMH cannot:
  - ▶ Release any medical records.
  - ▶ Confirm if a person was ever served by DMH.
  - ▶ Confirm whether records are still under DMH's custody or control.

# Questions/Feedback

## Regulations Governing Access to Patient Records

# Record Collections Held by Secretary of the Commonwealth: State Library of MA

- ▶ Public Document Series
  - ▶ Annual reports from state hospitals and asylums, vital statistics, boards of charity, health, and insanity, among many others.
  - ▶ Provide insights into how these institutions were run in the past
  - ▶ Available online through the library's digital collection: <https://archives.lib.state.ma.us/home>



# Record Collections Held by the Secretary of the Commonwealth: MA State Archives

## ▶ Human Services Collection:

### ▶ Lists the institutional records from DMH and DDS:

- ▶ Medical Records (restricted)
- ▶ Registration Information (restricted)
- ▶ Business Records
- ▶ Death Records
- ▶ Cemetery/Burial Records

## ▶ Access to Human Services Collection:

- ▶ Policy allows access to most records typically after a 75-year waiting period.
- ▶ Timeline is not explicitly set in Massachusetts General Law and may vary depending on the type of record and any associated restrictions.



# Collections Held at the Massachusetts State Archives

Boston State Hospital: 1856-1985	Medfield State Hospital: 1896-1948
Bridgewater State Hospital: 1887-1967	Metropolitan State Hospital: 1930-1992
Danvers State Hospital: 1878-1980	Northampton State Hospital: 1858-1993
Fernald State School: 1852-1969	Tewksbury State: 1860-1896
Grafton State Hospital: 1877-1955	Westborough State Hospital: 1886-1960, 1970-1977

# Questions/Feedback

## Record Collections Held by the Secretary of the Commonwealth

# Records Held by DMH and DDS

## ▶ Storage Locations and Conditions:

- ▶ Active DDS and DMH facilities
- ▶ Area and Central offices of each agency
- ▶ Old buildings on institutional campuses still open
  - ▶ Storage conditions lack important safeguards (e.g., sprinkler and heating/ventilation systems).
- ▶ Most records are in paper form, which makes them more likely to get damaged by things like humidity, light, and age.
- ▶ Question of storage capacity at the MA Archives

# DDS and DMH Facility Storage Examples

- ▶ Medfield State Hospital: Records likely stored in unsafe buildings; can't enter
  - ▶ SCSI has asked EOHHS when the buildings will be inspected
- ▶ Fernald State School: Records with PII found in old campus buildings in 2024
  - ▶ DDS has taken action to retrieve records found in unsecured buildings
- ▶ Wrentham Developmental Center: In 2024 someone trespassed and broke into a closed building and found old records from another state school stored there
  - ▶ DDS has taken extra security measures, but challenges remain.
- ▶ Paul A Dever State School (2014): Records from the 1960's were found and left unsecured in an old campus building
  - ▶ Similar discoveries made at other closed state hospitals by urban explorers
- ▶ Foxborough State Hospital (2000): Patient records not stored at the State Archives, and some are Taunton State Hospital
  - ▶ Many records are presumed to be missing

# Questions/Feedback

## Records Held by DMH and DDS

# Private Collections of Institutional Records

- ▶ Many old records are held by private libraries in different institutions like colleges and universities.
- ▶ Private collections have different record access rules:
  - ▶ National Security Risk: May contain information that could pose a risk.
  - ▶ Privacy Laws: May include sensitive personal or medical information.
  - ▶ Preservation Needs: Fragile, old records restricted to protect condition.
  - ▶ Donor Agreements: Restrictions may be set by donors, such as limited access or delayed availability.
- ▶ Some records may not be available because they are “unprocessed.”

# Countway Library at Harvard Medical School

- ▶ 15 different collections of records related to state institutions:
  - ▶ Patient Information: Includes consent forms for experiments, test results, autopsy reports, case studies, and patient records, which some include personal identifiers (e.g., names), initials or numbers.
  - ▶ Research Findings: Detailed studies and records of clinical studies conducted in state hospitals.
  - ▶ Institutional Oversight: Records of hospital operations, including inspection reports and patient care documentation.
  - ▶ Trustee Reports: Includes Trustee meeting minutes, reports on the conditions of care, and significant events in the hospitals.
  - ▶ Surplus Records: Some records were considered surplus by the State and transferred to the Countway Library for preservation.

# Countway Access Rules and Restrictions

- ▶ Institutional Review Board (IRB) regulates access to patient records.
  - ▶ Researchers or individuals must get IRB approval to access sensitive data
  - ▶ In most collections, patient records **are closed for 80 years** from the date of creation to protect patient privacy.
    - ▶ Access granted earlier upon approval from the Institutional Review Board
  - ▶ Reports about hospital management may be restricted if they contain sensitive details about abuse or operational practices.
- ▶ The State Archives is aware of the private collections housed at Countway, and there is collaboration between these two institutions, especially regarding the handling of closed records.

# Yakovlev-Haleem Collection (1926 – 1936)

- ▶ Dr. Yakovlev was a physician who worked at the Monson State Hospital for Epileptics, Metropolitan State Hospital, and Fernald.
  - ▶ Conducted studies on patient brains to learn about causes of disabilities
  - ▶ Collection has 900 + brains that were curated by Mohamad Haleem
- ▶ Collection is part of the Neuroanatomical Collections of the National Museum of Health and Medicine.
  - ▶ Not available to the public but can be viewed by qualified researchers by appointment
  - ▶ Parts of the collection were once held by the Eunice Kennedy Shriver Center; also transferred to National Museum of Health and Medicine.

# Belchertown State School Friends Association

- ▶ Housed at University of Massachusetts Amherst
- ▶ Records related to the Belchertown State School
  - ▶ Legal cases associated with the institution
    - ▶ Massachusetts v. Russell W. Daniels
    - ▶ Ricci v. Greenblatt (later Ricci v. Okin)
- ▶ Open for research without restrictions

# Samuel Bayard Woodward (1832 – 1846)

- ▶ Housed at University of Massachusetts Chan Medical School
- ▶ Dr. Samuel Bayard Woodward
  - ▶ First superintendent of the State Lunatic Hospital in Worcester
  - ▶ Co-founder of the Association of Medical Superintendents of American Institutions for the Insane
- ▶ Collection is digitized and includes writings by Woodward, such as essays, addresses, obituaries, letters, and verses.
- ▶ Open for research without restrictions

# Samuel Gridley Howe Library

- ▶ Housed at Brandeis University - Robert D. Farber University Archives
- ▶ Collection includes a diverse range of materials related to the Walter E. Fernald Developmental Center.
- ▶ The collection was transferred to Brandeis in 2010 after the closure of the Howe Library on the Fernald campus.
- ▶ The collection contains books, papers, case studies, pamphlets, and journals on topics like eugenics, mental disabilities, and disability studies.
- ▶ It includes materials from prominent figures in the disabilities field (Irving Kenneth Zola and Rosemary and Gunnar Dybwad)
- ▶ The collection is not yet processed, but once it is, materials containing patient information will likely have restricted access.

# Questions/Feedback

## Private Record Collections

# Personal Experiences Attempts to Access Institutional Records

- ▶ How the Information was Collected
  - ▶ Four key Informant Interviews conducted by CDDER with family members of former residents of state institutions who attempted to access their deceased family member's records from state institutions.
  - ▶ Referenced books written by local authors who documented their experiences accessing records from state institutions when researching their family history

# Key Themes from Interviews

- ▶ Barriers to Accessing Records:
  - ▶ Legal barriers, such as the need for probate court orders or specific permissions, were significant obstacles in all cases.
- ▶ Problems with Record Keeping:
  - ▶ Records were poorly maintained or destroyed over time.
  - ▶ Records were transferred to other institutions.
  - ▶ Some key informants being unsure whether records even still existed.
  - ▶ Records were scattered, inaccessible or in danger of being destroyed.
- ▶ Desire to Understand Family History:
  - ▶ These searches are not just about obtaining information—Key informants describe a deep, emotional need to understand the lives of family members who were separated from them due to institutionalization.

# Advocacy for Change

- ▶ Key Informants called for more transparency and accountability in the records access process.
- ▶ Criticism of the system which they say as for prioritizing staff privacy over that of the former residents.
- ▶ Advocate for the creation of funds to help families navigate the probate process.
- ▶ Would like for public acknowledgment of the history of institutions like Fernald and apologies for the mishandling of records.

# Questions/Feedback

## Personal Experiences

# Areas for Additional Research

- ▶ Evolution of Governing Bodies of State Institutions (to present day)
- ▶ Changes to the Statewide Record Retention Requirements
- ▶ Records stored at DMH and DDS Facilities and Offices
- ▶ Summary of Records Destroyed
- ▶ Records from State Institutions available online
- ▶ Researcher Access to Records
- ▶ Harvard Legal Clinic Analysis
  - ▶ Comparative Standards from other States
    - ▶ Records Access
    - ▶ Death/Cemetery Records and HIPAA

# Framework for Remembrance Summary of Draft Report

# Framework for Remembrance

## Major Topics

- ▶ Summary of Remembrance Projects
  - ▶ Belchertown State School Friends Association
  - ▶ Danvers State Memorial Committee
  - ▶ California Memorial Project
  - ▶ Willowbrook Mile
- ▶ Key Themes and Lessons Learned
- ▶ Areas for Additional Research

# The Belchertown State School Friends Association

- ▶ Focus on establishing a memorial and museum at the site of the former Belchertown State School.
- ▶ The memorial will provide a space to share the history of special education, institutionalization, and the broader story of disability rights.
- ▶ The group's mission includes preserving the state school administration building and offering community space for education and reflection.
- ▶ In partnership with the Belchertown Historic Commission and the Belchertown Cultural Alliance, the Friends Association is working on projects such as an interpretive trail and museum.

# Danvers State Memorial Committee

- ▶ The Danvers State Memorial Committee was led by former patients and community advocates that focused on the restoration and proper memorialization of the neglected cemeteries at Danvers State Hospital.
- ▶ Understood the importance of land redevelopment and influenced plans for the property
  - ▶ Proceeds from its sale would be used to create adequate housing for individuals with mental health needs.
  - ▶ Responsibilities for the care and maintenance of the cemeteries were included in the sale of the land
- ▶ Efforts were rooted in a desire to honor the past while fostering a more inclusive future

# California Memorial Project

- ▶ The California Memorial Project was established and is run by peer advocates
- ▶ Dedicated to honoring individuals with mental health and developmental disabilities who lived and died in California state institutions.
- ▶ Over 45,000 people lived in California state institutions, many of whom were buried in unmarked graves without recognition.
- ▶ Established in 2002 through legislation (Senate Bill 1448)
  - ▶ Cemetery restoration projects
  - ▶ Annual Day of Remembrance across the state each year on the 3<sup>rd</sup> Monday in September
- ▶ Annual remembrance ceremonies include speeches, personal stories, and artistic contributions.
- ▶ Oral Histories are being recorded and posted on the project's website

# The Willowbrook Mile Walking Trail

- ▶ Remembers the history of Willowbrook State School in Staten Island, NY
- ▶ The trail has 12 stops that tell the story of the school and the challenges the people who lived there faced
- ▶ It is designed to be accessible so that everyone, no matter their abilities, can learn about Willowbrook's history.
  - ▶ Pathways are wheelchair-friendly, with smooth surfaces, ramps, and benches
  - ▶ Information panels feature large print and braille, and guided audio tours
  - ▶ ASL interpreters available, and video presentations include captions.
  - ▶ Materials in Plain and other languages to accommodate non-English speakers
- ▶ The Mile is a powerful tool for education and advocacy-ensuring the history of the institution is remembered and promoting greater inclusion and justice for people with disabilities.

# Questions/Feedback

## Summary of Remembrance Projects

# Key Themes

- ▶ **Collaboration with Stakeholders:** Former residents, families, advocates, government agencies, and community
  - ▶ Ensures a broad range of perspectives are included
  - ▶ Honors the diverse histories of the individuals involved
- ▶ **Inclusivity and Accessibility:** Design with accessibility in mind
  - ▶ Create spaces that are welcoming and engaging for individuals with a wide range of physical, sensory, and cognitive abilities.
- ▶ **Focus on Education and Reflection:** Provide educational opportunities
  - ▶ Museums, trails, and interpretive materials
  - ▶ History of institutionalization and the social justice issues surrounding disability rights
- ▶ **Community Engagement and Advocacy:** Remembering and honoring the past
  - ▶ Advocate for systems change and improved care for individuals with disabilities.

# Lessons Learned: Organizing

- ▶ **Know Your Stakeholders:** Involve a wide range of people from the beginning, including families, advocates, and officials. This makes sure the project reflects many viewpoints.
- ▶ **Encourage Member Voices:** Let people with lived experiences share their stories. Listening to former patients helps build trust and involvement.
- ▶ **Create a Shared Vision:** Work together to form a common goal. A united vision helps everyone feel invested in the project.
- ▶ **Take Time to Plan:** Plan carefully but be flexible. Big projects take time and need proper planning, like securing funding or handling unexpected problems.
- ▶ **Safeguard Your Message:** Stay true to the mission. Don't let outside pressures distract you from the main goal.
- ▶ **Be Ready for a Long Ride:** Advocacy projects can take years. Stay patient and keep pushing for the change you want, even when it's slow.

# Lessons Learned: Supporting People with Lived Experience

- ▶ **Prepare Agendas:** Organize meetings with clear agendas to stay on track. This helps members feel prepared and valued.
- ▶ **Foster a Respectful Atmosphere:** Create a space where everyone feels heard and respected, even if they have different opinions.
- ▶ **Level the Playing Field:** Encourage open communication by treating everyone equally. This helps people feel comfortable sharing their ideas.
- ▶ **Recognize Diverse Leadership Styles:** Not all leaders are the same. Some lead by listening or organizing, so appreciate all kinds of leadership.
- ▶ **Cultivate Leadership Skills:** Give members the chance to practice leadership, like public speaking, so they can feel confident.
- ▶ **Engage the General Membership:** Keep members involved by hosting regular events and encouraging them to share their thoughts and memories.
- ▶ **Invite Participation in Public Forums:** Encourage members to attend public meetings where they can share their views and help shape decisions.

# Areas for Additional Research

- ▶ MetFern Cemetery Restoration
- ▶ Westborough Cemetery Project
- ▶ DDS Cemetery Restoration and Annual Memorial Ceremonies

# Questions/Feedback

## Key Themes and Lessons Learned

# Next Steps

- ▶ Vote to Adjourn