



Special Commission on State Institutions

January 18, 2024
3:00 - 4:30 pm

Virtual / Zoom

Evelyn Mateo
Co-chair

Matt Millett
Co-chair



Agenda



- 1. Welcome and Introductions of CDDER Team**
- 2. Vote to approve minutes from 10/20/2023 meeting**
- 3. Discussion of support for the Commission's work**
- 4. Discussion of Boston Globe Article**
- 5. Plans for goals of the Special Commission**
 - a. Goals 1 and 2: Existing records and request process**
 - b. Goals 3 and 4: Burial locations**
 - c. Goal 5: Framework for public recognition**
- 6. Next Steps**



The CDDER team who will be helping the Commission with this work.

- Dr. Emily Lauer - CDDER Director
- Jennifer Fuglestad - Sr Quality Improvement Specialist
- Christine Roa - Project Manager

We have set up an email address that we will use to communicate with Commission members. The address is SCSI_Support@umassmed.edu.

Special Commission on State Institutions

Emily Lauer, PhD, MPH

Director & Associate Professor in Family Medicine and
Community Health



Center for Developmental
Disabilities Evaluation and
Research (CDDER)

Discussion of support for the Commission's work

- a) Update on agreement with CDDER
- b) Timeline of available funding
- c) SCSI You tube channel
- d) Presentation Template
- e) Working groups
- f) Meeting schedule

News Coverage Regarding Patient Records from Former Institutions

- *Grave Records Lost* The Sun Chronical November 2000
 - Article regarding missing records from Foxboro State Hospital
- *State sweeping shuttered buildings for medical records after questions from FOX Undercover* Fox News January 2014
 - Confidential records found in The Paul A Dever School and The Metropolitan State Hospital by ‘urban explorers’
- *The shameful afterlife of the Fernald School in Waltham* The Boston Globe 1/10/24

Commission Input

- **Does the Commission want to take some action in response to the Globe article?**
 - Example options:
 - Letter of response to send to the Globe
 - Letter of Inquiry to look into the facts
 - Do nothing publicly
- **If yes, propose a working group to draft content**

Goals of the Special Commission

Goals 1 and 2: Existing Records and Request Process

Goals 3 and 4: Burial Locations

Goal 5: Framework for Public Recognition

Decisions:

- **What do we mean by “Institution”?**
- **What will be included in the scope of what this Commission reviews?**
- CDDER proposes a working group to get into the details. This group could then come back to the Commission to make a recommendation for approval.

MA Public Institution System

Between 1830 to 1930, the Commonwealth created a public institutional system. Over 30 sites were constructed across the state including:

- State psychiatric hospitals
- Schools and one farm for people with IDD
- Reform schools for juveniles
- Almshouses for the poor
- Sanatoria for tubercular patients
- Specialized institutions for alcoholics, for children with physical disabilities, and for laboratory research

More currently:

- Intermediate Care Facilities for Individuals with Intellectual Disabilities (1988-present)

Goals 1 and 2: Existing records and request process

What CDDER has found to date

Types of Records Kept by Institutions

1. Medical records.

- Health information about people
- Protected by U.S. and Massachusetts laws. These laws limit access to recent records of people receiving services.

2. Registration information.

- This is information collected when someone comes to an institution for their first time, like their name, date, age, their family and other details.
- Sometimes they have information about when they leave an institution, or if they die.

3. Business Records and Reports.

- This is information about the institution, like pictures and maps of the facility, how many people come and leave, and the types of services they had.

Holders of Institutional Records

- Records are held in many different libraries.
 - Public and Private Universities
 - State and City Archives
- Many patient records and other files have restricted public access due to medical privacy laws.
 - Restriction is generally 75-80 years after the creation of the file
- Some records are under other restrictions that are up to a librarian or archivist. Access to these records may be given on a case-by-case basis.

Obtaining Institutional Records in MA

Privacy laws limit what information can be given out about a person who got services from an institution.

The law says only people with a legal right can get these records, like.

- The person in charge of the money and property of someone who has died.
- Lawyers who have permission from the person. If they are dead, lawyers who are working with the person in charge of their money and property.
- People who a court says can get the information

Often, people have to pay a lawyer between \$2,500 - \$3,000 to help get records.

Goals 1 & 2: Plans for next steps

- CDDER will work with the Commission to figure out:
 - **What types of records should be included?**
- Next, CDDER plans to talk to more people who:
 - Know more about where records are kept
 - May know more about which records exist and which are missing
 - Have been trying to get records like this
- These include people who work at libraries and archives, have studied these records, or who may have been in charge of these records or moving the records after an institution closed.
- **Who else should we talk to?**
- **Are there other steps you'd like us to take next?**

Goals 3 and 4: Burial Locations

What CDDER has found to date

Burial Locations

- There are cemeteries on the grounds of former state institutions.
 - Most of these cemeteries from the sites called institutions are still owned by the State of Massachusetts
- Some people who died in institutions were buried in “pauper” cemeteries or in the local parish cemetery
- Many of the cemeteries have unmarked graves
 - Markers often only include an identification number
 - Some markers show whether the person was Catholic or Protestant.

Burial Locations

- Grave Markers and Burial Records have been lost for some cemeteries
 - Northampton
 - Foxboro
- Burial records are often held by a state agency and are not available to the public
- For some cemeteries, the total number of former residents who are buried there has not been counted.

Commission Input on Goals 3&4

For further discussion:

- **Who should we talk to?**
- **Which Cemeteries are in scope?**

Goals 5: Framework for Public Recognition

What CDDER has found to date

Examples of Memorials in MA

- Cemetery Restoration Projects
 - Projects run by former patients and families, staff, disability advocates and allies and the local community.
- Wrentham State School Memorial Walk
- Friends of Belchertown State School

Examples of Memorials- Other States

- California Memorial Project (CMP)
- The Mansfield Training School Memorial and Museum
- Minnesota - Remembering with Dignity
- Mississippi - Asylum Hill Project
- New York - The Willowbrook Project
- Oregon - the Oregon State Hospital Memorial
- Pennsylvania - Pennhurst Memorial and Preservation Alliance
- Vermont- 20th Anniversary of the Closing of Brandon Training School Events

Developing a Memorial

- The projects take time (many years) and lots of planning
- Needs a good Action Plan with the goals of the Memorial
 - Who will be involved? How will they be organized?
 - Think about stakeholders, like former patients/residents; self advocates; advocacy groups; families; allies; state agencies; local communities
 - What do we want to develop, and how will we do it?
 - Annual Events? Who will plan and carry out? In person or virtual?
 - If we want to build a memorial or museum, where? Who designs/builds it?
 - How do we pay for it?
 - How do we do it? Need a plan to get the right permissions, permits, how to cut through “red tape”. How/when to involve media?

Commission Input on Goal 5

- For further discussion in working group:
 - Review what other states have done and the work involved
 - Start to draft a planning document with all of the decisions that need to be made
- **Are there other people you'd like us to talk to next?**

Next Steps

- Sign up for working groups by emailing Matt Millett and Evelyn Mateo and cc SCSI_Support@umassmed.edu