### **Special Commission on State Institutions**

May 8, 2025 3:00PM – 5:00PM

#### Virtual / Zoom

Dr. Kate Benson Co-chair Anne Fracht Co-chair

**SCS** Massachusetts Special Commission on State Institutions

## Agenda

- 1. Welcome and Announcements
- 2. Recap of Last Meeting
- 3. Vote to Approve 4/10/25 Meeting Minutes
- 4. Proposed Recommendations
- 5. Next Steps
- 6. Vote to Adjourn



### **Welcome and Announcements**

### Announcements

- 100<sup>th</sup> Anniversary of the opening of the Belchertown State School Cemetery- Memorial Service on May 23<sup>rd</sup> at 1:30 pm
- Recent fire on the grounds of the former Fernald State School
- Recap of Last Meeting
- Vote to approve 4/10/25 meeting minutes



# **Stakeholder Feedback and Updates**



# **Records and Records Access**

# **Proposed Recommendation**



## **Recommendation: Records and Records Access**

- Modify Laws Regarding Restricted Medical Records
  - Change existing laws to allow family members/descendants to access medical records within 50 years of an individual's death upon proving the person is deceased.
  - This would eliminate the need for court orders, which can be costly and complex, and ensure records are made available with privacy protections in place.



# Discussion

### Modify Laws Regarding Restricted Medical Records



# **Burials and Burial Locations**

# **Proposed Recommendations**



### **Recommendation Groupings**

- Recommendations Related to Known & Unknown Burial Grounds
- Recommendations Related to Disabled Dead Practices and Laws



### **Recommendation: Locating Unmarked Graves on Former Institutional Properties**

- The Commonwealth of Massachusetts should initiate a formal effort to:
  - Investigate and map the potential locations of unmarked graves
  - Focus on former state institutional properties where deceased individuals may have been buried without markers
- Why This Is Important
- Understanding the scope and location of unmarked graves is essential for:
  - Historical accountability
  - Respectful memorialization
  - Addressing long-standing community concerns
  - Enables future restoration and protection efforts

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## **Recommendation: Guidelines for Institutional Cemetery Stewardship**

- The Commonwealth should establish clear, formal guidelines governing:
  - Investigation of institutional cemeteries
  - Restoration practices
  - Long-term maintenance and protection
- Why This Is Important
  - Prevents irreversible damage or desecration, even from well-intentioned efforts
  - Provides consistent standards across all state institutional cemetery sites
  - Ensures that restoration and maintenance practices are respectful, coordinated, and informed by disability justice principles



# **Recommendation: Establish a Perpetual Care Fund**

- Dedicated to the long-term maintenance of institutional cemeteries and cover upkeep activities such as:
  - Landscaping
  - Road maintenance
  - General grounds care
- Award grants to community groups to support creation of memorials at burial sites of former patients and residents of Massachusetts institutions.
- Why This Is Important
  - The state must take long-term responsibility for cemetery care
  - Ensures respectful remembrance and upkeep of burial grounds tied to the history of state institutions



# Discussion

### Recommendations Related to Known & Unknown Burial Grounds



# **5 Minute Break**



# Disabled Dead Practices and Laws

### Recommendations



### **Recommendation: Repeal Chapter 113**

#### **Overview of Chapter 113**

- Requires state institutions to transfer unclaimed bodies of deceased patients to medical schools
  - Bodies were used for anatomical dissection and educational purposes
- Why This Is Important
- No longer reflective of current medical education practices
  - Today, requests for unclaimed bodies from state institutions is rare/replaced by voluntary body donation programs
- Repeal would protect the dignity and rights of the deceased



# **Recommendation: Formal Apology & Registry of Remains**

- Medical schools, institutions, and government agencies that used the bodies of disabled individuals without consent for research must:
  - Create a public registry of any remains or related materials
  - Issue a formal apology for these past practices
- Registry would allow descendants and loved ones to locate remains and understand the history
- Why This Is Important
  - Acknowledges and addresses past harm done without consent
  - Ensures transparency and accountability for those who benefited—financially or intellectually—from these practices
  - Supports healing for families and communities impacted by the historical treatment of the disabled dead



# Discussion

### **Recommendations Related to Disabled Dead Practices and Laws**



# Framework of Remembrance

# **Proposed Recommendations**



## **Recommendation: Museum & Memorialization Initiatives**

Create a statewide museum and resource hub to:

- Preserve institutional history and honor former residents
- Tell the stories of the independent living movement, deinstitutionalization, and disability inclusion
- Recommend forming a member-led feasibility committee to Deliver a report on potential physical and digital models



# **Discussion** Museum & Memorialization Initiatives



# Recommendation: Formal State Apology

- The Commonwealth of Massachusetts should issue a formal apology to address:
  - Neglect of institutional cemeteries
  - Mishandling of records
  - Systemic harm done to disabled individuals in state institutions
- Why This Is Important
  - Acknowledges that while some received care, many others were harmed
  - Confronts a legacy of institutionalization that often failed to prioritize the wellbeing of disabled people
  - A formal apology would be a powerful act of recognition, helping survivors and descendants begin to heal
  - Reinforces the state's commitment to accountability and disability justice



# **Discussion** Formal State Apology



## **Recommendation: Integrating Disability History into K–12 Education**

- Commit to incorporating disability history in Massachusetts into the public-school social studies curriculum with a focus on:
  - Institutional history and its impact on individuals and communities
  - ► The evolution of disability rights, advocacy, and inclusion
  - Connections between past injustices and present-day progress
- Why This Is Important
  - Ensure that disabled students see themselves reflected in the historical narrative
  - Help all students understand:
    - The mistreatment and resilience of disabled people
    - How this history informs our current values, systems, and reforms

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# **Discussion** Disability History into K–12 Education



### **Other Recommendations?**

## What else should we consider?



### **Next Steps**

Vote to Adjourn

