



Established in 2023

## Special Commission on State Institutions Overview and Recommendations

May 15, 2025

People with intellectual, developmental, and mental health-based disabilities face significant barriers to equality, including segregation, discrimination, and violence. The Special Commission on State Institutions was established by the Commonwealth of Massachusetts in 2023 to explore potential connections between these barriers to equality and the Commonwealth's history of incarcerating disabled people in large-scale institutions.

Our two-year investigation is the first state-sanctioned human rights inquiry into institutionalization led by people with disabilities. It came about because of widespread concern that the documents and records that tell the story of the state's treatment of people with disabilities were being kept from survivors, descendants, scholars, and the public, while the records themselves were being mishandled, lost, sold on private markets, and destroyed. Equally concerning were the deteriorated conditions of institutional cemeteries which contain thousands of anonymous graves. All the while former institutional sites were being neglected, left to vandals, and repurposed by communities in ways that trivialized or whitewashed a history many do not seem to know.

This is no small matter. The ways that Americans think about disabled people have been shaped by Massachusetts and that has been the case for nearly two centuries. In large part, that is because Massachusetts developed, sustained, and exported many of the first legal, medical, educational, charitable, and social systems for placing people with intellectual, developmental, and mental health disabilities in institutions: practices widely understood for more than 75 years to be a violation of fundamental human rights.

The Massachusetts School for Idiotic and Feeble-Minded Youth (later called the Walter E. Fernald Developmental Center) was the nation's first public institution for people with intellectual and developmental disabilities. The Worcester State Hospital was among the nation's first state hospital asylums for people with mental illness. The champions of these institutions, Samuel Gridley Howe and Dorothea Dix, ushered in an age of institutionalization that exists to this day. At its height in the not-too-distant past, Massachusetts was home to a network of twenty-five state

schools, state hospitals asylums, and similar institutions that housed tens of thousands of people, while the nation's institutions housed nearly one million.

Millions of documents in the possession of the Commonwealth tell the stories of the people whose lives were shaped by these institutions, as do the thousands of institutional graves that dot our landscape from Boston to Belchertown, Northampton, Westborough, and Waltham. The state's records include the names of those people, many of whom were buried in nameless graves, along with clues about whether there may be unmarked graves. They include more than 150 years of patient files and letters. They include crucial documents written by the people who built and sustained these institutions. They also include human remains, used for study by major medical institutions and the state, often without consent. Collectively, theirs is a story of one of the most overlooked human rights tragedies in American history with crucial lessons for learning how not to re-create those tragedies today.

As we have uncovered, a pattern of practices, intentional and unintentional, have prevented the general public from accessing this history, even when the people requesting that access are institutional survivors, their loved ones, and their descendants. Records of all kinds are held by private institutions that should not hold them and have been left exposed to vandals who photograph and sell them online, all while citizens seeking the very same information face insurmountable legal, procedural, and financial barriers to access. By hiding a story of mass human rights abuses the Commonwealth is preventing society from engaging in a full reckoning with the atrocities that have been inflicted on disabled people throughout our history.

These acts of erasure have caused untold harm. Thousands of institutional survivors have died awaiting a formal apology from the Commonwealth of Massachusetts that has never been issued. Instead, the state has weaponized claims about protecting patient privacy to an extreme degree, often far beyond the federal government, in ways that serve its interests at the expense of the public interest. Precisely because the public is largely unaware of the countless tragedies inflicted by these institutions—tragedies told in this hidden history—people with disabilities today face very-real threats by the non-disabled including the revival of large-scale institutionalization where the practice has been abolished, and its expansion where it stubbornly remains.

In this overview, we provide a summary of our findings and recommendations for stakeholders in state government and civil society. This summary includes a high-level overview as well as specific target areas for action on records, burials, and steps that the Commonwealth must take to ensure that current and future generations know the vitally important stories of what society and the state have done to our disabled friends, colleagues, neighbors, and forbears. Our comprehensive report of findings, created by the UMass Chan Medical School Center for Developmental Disabilities Evaluation and Research follows this summary and is included for reference and use.

A majority of our commission's members are disabled. We serve in government agencies,

disability rights groups, and academic institutions. We bring centuries of combined professional experience in disability law, policy, service, education, and advocacy to our work. We also have significant lived experience. Many of us have spent pivotal moments in our lives, sometimes for sustained periods of time, living out the history we have been entrusted to explore, including living in large-scale institutions or under the guardianship of the state. What we have found in the subsequent report is shocking and demands immediate action.

Above all else, it is the unanimous agreement of the commissioners that the state must acknowledge the enormity of the legacy and harm of mass institutionalization that reverberates today. For that to begin, an apology is owed.

## A Framework for Public Recognition

*“The Commission shall...design a framework for public recognition of the commonwealth's guardianship of residents with disabilities throughout history, which may include, but shall not be limited to, recommendations for memorialization and public education on the history and current state of the independent living movement, deinstitutionalization and the inclusion of people with disabilities.” – Enabling Statute, Section 144*

### Accountability for Systematic Erasure

Our recommendations are based on a sobering reality. Disabled people—including institutional survivors—have largely been excluded from leading community efforts to re-use and reckon with former institutional sites. As a result, our history is systematically erased through disuse, vandalism, and insensitive redevelopment of sites in ways that trivialize the significance of what was done. At their most offensive, sites have been used for pornographic photo shoots, white supremacist celebrations, community festivals, and amusement parks that would never be tolerated at similar sites of significant human rights abuses in Massachusetts or America.

These actions are the result of widespread public ignorance of the history of disabilities, de-institutionalization, and independent living in Massachusetts. They arise in large part from the state's improper handling of records and burials recounted below. We ignore this history at the grave peril of repeating it in the present day. This can only begin to change when the Commonwealth acknowledges the scope of the tragedies enumerated in the report included here.

### Recommendations

1. **A Formal State Apology:** The Commonwealth of Massachusetts, through action of its executive officer, Governor Maura Healey, should issue a formal apology for the neglect of many state institutional cemeteries, the damage caused by the gross mishandling of records, and the ways in which state institutions often hurt, rather than helped the disabled people entrusted to their care.

While it is true that a small number of people received treatment and relief in these settings, it is unquestionable that most—including thousands who are alive today—were not helped by a system maintained for reasons that did not place the health and well-being of inmates<sup>1</sup> at the fore.

Numerous states have issued similar statements regarding aspects of their institutional histories, including Georgia, South Carolina, Virginia, California, Oregon, Wisconsin. So too did President Bill Clinton regarding the use of radioactive tracers on unsuspecting disabled inmates of the Fernald and Wrentham State Schools here in Massachusetts.

It has been three decades since the president’s apology. It is time that Governor Healey and the legislature do the same for the state where disability institutions first gained a systemic foothold and were propagated to the rest of the nation and world.

2. **Museum & Memorialization:** The Commonwealth faces sobering financial realities, many of which have the potential to negatively impact the lives of disabled people. The needs of our fellow disabled people come first.

Nonetheless, there must be an organized effort to dedicate funding and museum space to supporting the public understanding of the state’s history of institutionalization and the independent living movement. There is also an absolute need for memorialization in a public and accessible place, where the lives of those who died in institutions are remembered. Both efforts must include leadership by disabled people.

Given present realities we call on the Governor to convene a feasibility committee comprised of—but not limited to—representatives from the Massachusetts Archives, disability communities, and the Massachusetts Cultural Council, to develop and deliver a report on options for potential physical and digital spaces.

3. **K-12 Public Education:** There must be a commitment to robust inclusion of the history of disability in Massachusetts in the social studies curriculum of our public schools, including the history of institutionalization and the history of the independent living movement, so that disabled students can see that their history is part of the larger fabric of American history and all students can understand what was done in the past and how it relates to and differs from our present day.

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<sup>1</sup> While the term “resident” or “client” is often used today, for a significant portion of the history of disability institutions in Massachusetts, disabled people were referred to as “inmates.”

# Institutional Cemeteries

*“The Commission shall...Assess and compile records of burial locations for the residents who died while in the care of such institutions...[and] [d]etermine the likelihood and possible locations of unmarked graves at sites of former state institutions for people with intellectual or developmental disabilities or mental health conditions.” – Enabling Statute, Section 144*

## Mistreatment of the Disabled Dead

One of the most disturbing issues confronted by the commission is the legacy of deaths and burials in state institutions. Only one third of the state’s 27 institutional burial grounds investigated by the commission have been restored and are presently maintained. More than 10,000 burials are located in decrepit or poorly maintained cemeteries. Most of these individuals were buried anonymously in graves marked without the name of the deceased, in cemeteries that fall under the jurisdiction of various towns and state agencies.

In our work, the Commission has created unprecedented agreements with the state to evaluate nameless burials at the cemetery of the former Foxboro State Hospital. But as we have also seen, the state chooses to treat burial information from cemeteries as medical records when they should be considered vital records. As a result, thousands of immediate family and descendants of people who died in institutions do not know where their loved ones are buried.

In some instances, the state’s reliance on grassroots initiatives to lead the restoration of cemeteries has made space for community leadership and buy-in, but in at least one other instance, the absence of clear authority has led to a grave-hunting expedition using methods expressly disapproved by the state archaeologist’s office. In another instance, a state agency offered to move the bodies of the disabled dead without community input or clear authority to do so in a proposal for private re-development opportunities at a former institutional site.

In addition to graves, the state has had a longstanding and legislatively-backed ability to give unclaimed bodies of deceased institutional inmates to medical schools for scientific and medical research. Government and university collections contain these human remains and have not undertaken efforts to document and make available their records in ways that are accessible by descendants.

Lastly, no systematic effort to look for unmarked graves has been undertaken by the Commonwealth at current and former institutional sites, raising the continued specter that remains will be found at some point—as has occurred elsewhere in the United States—and that ongoing development of former institutional sites without sufficient state oversight, is eradicating potential evidence.

Due to the records access issues enumerated in the Records section below, the commission is unable to confirm or deny the existence of unmarked graves or a full tally of the whereabouts of human remains taken for scientific and medical research. But credible evidence has emerged near the close of our work, indicating that at least one former institutional site is a site of unmarked graves.

Given these realities, the state must take straightforward steps to address these issues.

## Recommendations

1. **Creation of a Perpetual Care Fund:** The creation of a Perpetual Care Fund to provide financial resources for the long-term maintenance of institutional cemeteries, including tasks like landscaping, road upkeep, and general grounds care. This fund could award grants to support community groups to create memorials at locations where former patients and residents of Massachusetts institutions are buried.
  - a. Stakeholders: Massachusetts Legislature, in consultation with the Division of Capital Asset Management and Maintenance
  - b. Time Frame: Current legislative session
  - c. Why is this important: Community efforts cannot fund restoration and maintenance. They should have a say in how cemeteries are restored but it must be done in consultation with the state, with disability agencies involved, and the state must assume long-term responsibility for the grounds of its cemeteries.
2. **Repeal of Chapter 113:** [Chapter 113 of the Massachusetts General Laws](#) allows medical schools to request and use unclaimed bodies from state institutions, broadly defined in ways that include existing state disability facilities, for scientific and medical research. Chapter 113 Section 4 states that bodies “shall be used only for the promotion of anatomical science in the commonwealth in such manner as not to outrage public feeling.”

We unequivocally state that the use of disabled bodies for such research under the conditions outlined in Chapter 113 outrage public feeling. Should the legislature and governor fail to act, we call on the Attorney General to forbid such uses as allowed under the act.

- a. Stakeholders: Massachusetts Legislature, Governor
  - b. Time Frame: Current legislative session
  - c. Why is this important: This outdated practice violates basic conditions for consent with populations whose rights have historically been abused.
3. **Registry on Remains and Formal Apology:** The U.S. Government, state government, and medical schools who used the bodies of the disabled dead for medical and scientific research without their consent should create a registry of their holdings so that loved ones and descendants can locate remains and issue a formal apology for these past practices.
  - a. Stakeholders: Medical schools and institutions; Government agencies
  - b. Time Frame: Work should commence immediately, accompanied by a formal statement to inform the public

- c. Why is this important: The scope of this issue must be fully understood and those who profited in any way, intellectually or financially, from this practice, and information should be made available to descendants.
- 4. **Locating Unmarked Graves:** The Commonwealth must make a formal effort to investigate and map the potential locations of unmarked graves, with a focus on former state institutional properties where deceased individuals may have been buried without markers
  - a. Stakeholders: State Archaeologist, Massachusetts Archives, Mass Developmental Disabilities Commission
  - b. Time Frame: Exploratory conversations should begin immediately.
  - c. Why is this important: Credible evidence has emerged regarding the potential for unmarked graves at a former state institution. There is a need for historical accountability, respectful memorialization, and addressing long-standing community concerns.
- 5. **Guidelines on Institutional Cemeteries:** The Commonwealth should promulgate clear guidelines for all issues relating to the investigation into, restoration of, and maintenance of state institutional cemeteries.
  - a. Stakeholders: State Archaeologist, Massachusetts Archives, Executive Office of Health and Human Services, Massachusetts Developmental Disabilities Council.
  - b. Time Frame: Formation of a group to develop recommendations should commence immediately.
  - c. Why is this important: As we have uncovered, the risk of irrevocable desecration, even by well-meaning community or state stakeholders, is too significant without guidelines.

## State Institutional Records

*“The Commission shall...Review existing records in the possession of the commonwealth related to the network of current and former state institutions for people with intellectual or developmental disabilities or mental health conditions [and] [e]xamine the current availability of, and barriers to accessing, records by former residents of such institutions, their descendants and relatives and the general public” – Enabling Statute, Section 144*

### Kinds of Records and the Stories They Tell

State institutions kept significant, detailed records about their activities and the disabled individuals entrusted to their care. While often biased and dated, these records are frequently the only material that disabled people, our loved ones, and our descendants will ever be able to read about a disabled person’s life in an institution.

Indeed, primary source documents – that is, the original records produced at the time – are a vital part of confronting and understanding history. No study of history is possible without primary sources. This goes not just for the academic history of state institutions, but also for one’s family and personal history, all of which are heavily restricted by the current laws surrounding medical records.



The historical record contained in these documents is also a necessary part of understanding and making reparations for the past. If we are not able to examine, study, and confront the historical record due to the existing laws and government routines, we will never be able to fully reckon with what has happened in our state.

## The Current State of Institutional Records

Massachusetts is to be commended for retaining a significant number of documents well past the time when document retention schedules would have allowed for their destruction. However, in many instances this preservation has been accidental, and the overall manner of records preservation, access, and ownership uncovered by the commission supports our conclusion that the public is being unfairly denied reasonable access to materials in ways that are improper, obscure a significant human rights tragedy, and safeguard the state from scrutiny and accountability for past actions.

Across the three state agencies tasked with institutional records retention and access—the Department of Mental Health (DMH), the Department of Developmental Services (DDS), and the Massachusetts Archives—there is little coordination or agreement on best practices for handling institutional records. Funding is scarce and does not enable agencies to fulfill their mandate to properly handle these records. Without modification to the state’s record retention schedules by the Records Conservation Board, any attempt to transfer documents from DMH and DDS to the State Archives, would mandate their destruction rather than their preservation: an irrevocable loss that cannot occur under any circumstance.

At DMH and DDS, employees are sometimes wholly unaware of how records should be handled, and unsubstantiated rumors about a lack of storage and management space at Mass Archives have led to the improper storage of documents in active and inactive DMH and DDS facilities.

During the course of our work, major breaches of protected information came to light as well. Private medical information protected by state and federal law is openly sold online in marketplaces like eBay. Tens of thousands of documents were left open to vandals in the former Walter E. Fernald Developmental Center by the City of Waltham and Department of Developmental Services, resulting in an investigation by the Federal Department of Health and Human Services. An urban explorer was able to walk through an open door and access substantial collections of medical records at the Wrentham Developmental Center.

These are not isolated issues. Sensitive medical information is scattered in buildings across the state and sometimes held under questionable terms by private universities, libraries, local historical societies, and individuals. Indeed, in the waning weeks of the commission’s work, we discovered yet another massive collection of patient files and records from the government’s 1990s inquiry into the use of human radiation on inmates of the Fernald and Wrentham State Schools. All the while, questionable interpretations of state and federal medical privacy laws have



caused a *de facto* prohibition on public access to nearly all institutional records.

## The Impact of the Current State of Institutional Records

There is a widespread and justifiable public perception that institutional records are inaccessible or do not exist. Indeed, some of our own members have shared that they were unaware that records about their lives in the care of the state could exist and that they could request access to them.

Through our review of records access policies and first-person statements by individuals who have tried to obtain records about loved ones who died in institutions we uncovered nearly insurmountable barriers that create this perception. For a person to even know if records about their life in institutions or the lives of their loved ones, the state demands that they possess significant financial means and legal expertise that are well beyond the reach of most individuals.

In our interviews, people who attempted to access records about their loved ones described emotional traumatizing interactions that reopened old wounds. Their requests for records were often treated as rare and unusual when in fact, an ongoing tally kept by our commission colleagues at the Massachusetts Archives shows that hundreds of requests for records are made and denied each year, often because an individual lacks the probate authority to be identified as next-of-kin to a long-deceased individual, the means to begin to gain that authority, or clear guidelines about what the state will consider acceptable proof of a relationship. Given that most individuals who died in institutions had no assets and many did not have direct descendants, interviewees felt the requirements were nonsensical at best.

While the state regularly denies public requests, it selectively makes exceptions to its own stated practices. For instance, while public requests for burial information from state institutional cemeteries is prohibited, the state has given non-state entities the right to access, publish, and sell census information that identifies institutional populations by name and date. Further, the state has published and made available historical reports that identify individuals by name and reveal medical information that the public cannot request.

While the state's self-exemptions do not include full individual medical files, each one undermines the iron-clad restrictions presented to the public when requests are made and contributes to the impression expressed in our informant interviews: that records are intentionally being kept from members of the public who have a vested interest in obtaining them while exceptions are made for others. Under such conditions, institutional survivors, scholars, community leaders, legislators, and members of the general public who seek to understand this history face nearly identical challenges.

It is unquestionable that the state is aware that its current approaches have this effect on individuals and equally aware that the combined impact results in a clear outcome: the public is nearly always barred from understanding and scrutinizing the Commonwealth's historical use of

institutional systems on disabled people and the state is protected from that scrutiny.

## Overview of Recommendations

We recognize that medical records are sensitive records and fully support the federal Health Insurance Portability and Accountability Act (HIPAA) which shields the non-descendants in the general public from accessing medical documents for fifty years after the death of an individual. However, the state's current practices impede those who should have access and apply the same degree of restrictiveness to documents in perpetuity, no matter how old.

Our recommendations, while not exhaustive, are intended to begin to lift the veil of secrecy around institutional records, ensure that individuals are prioritized in their requests above the needs of the state, and properly balance the public interest with the state's responsibilities to safeguard individual privacy in accordance with state and federal law.

They fall into four large categories:

- Recommendations for Changes to management, preservation, and access rules.
- Recommendations for Changes to laws around record access.
- Recommendations to Improve access for former patients/residents or their families and researchers.
- Recommendations to Create a pathways for the return of institutional records to Massachusetts Archives.

Being that those in the archives profession are trained on how to deal with privacy, restrictions, and sensitive information contained within historical records, our recommendations place the Massachusetts Archives at the center of a restorative records preservation and access policy for the Commonwealth of Massachusetts. The Archives must receive commensurate funding to ensure such a mandate is fulfilled.

Each recommendation below identifies stakeholders whose are responsible for taking such actions, parties who should be consulted in the formulation of those actions, and the time frame by which these actions should be accomplished. Most of the recommendations herein can and should be implemented in a reasonable timeframe not exceeding one year.

The first item enumerated in Category I and the first item enumerated in Category II below—a temporary moratorium on the destruction of institutional documents and the passage of legislation regarding public access to historical records—must be taken immediately.

## Recommendations

### Category I: Recommendations for changes to management, preservation, and access rules

1. **Issue a temporary moratorium on the destruction of institutional documents** scheduled for destruction in the state's record retention schedules until such time as the recommendations herein have been completed.
  - a. Stakeholders: Governor in consultation with Attorney General and Records Conservation Board
  - b. Time Frame: Immediate
  - c. Why is this important: Per items 2 and 3 below, no effort to address the issues identified in this report with the actions enumerated below can proceed without an immediate halt to record destruction until such time as these steps are comprehensively put in place.
2. **Identify an agreed-upon set of historical records sub-categories for retention.**
  - a. Stakeholders: Massachusetts Archives Department of Mental Health, Department of Developmental Services, Records Conservation Board
  - b. Time Frame: Immediate
  - c. Why is this important: Not all records can be kept. The state should prioritize the creation of categorical definitions for documents that will be of primary importance and historical significance to institutional survivors, their families, descendants, and scholars, while accepting that many day-to-day administrative records cannot be preserved.
3. **Revise the state's document retention schedules for institutional documents** to ensure preservation of historically significant record categories when transferred from the Executive Office of Health and Human Services to the Massachusetts Archives.
  - a. Stakeholders: Department of Mental Health, Department of Developmental Services, Massachusetts Archives, Records Conservation Board
  - b. Time Frame: Immediate
  - c. Why is this important: If DMH, DDS, and EOHHS attempted to transfer the documents described in this report to Mass Archives today, the current record retention schedules would force Mass Archives to have to destroy them.
4. **DDS and DMH develop a clear, coherent, and consistent workflow with Archives** for handling these requests. DDS and DMH allow Archives to disclose whether Archives holds a file for an individual if a researcher has their name and some identifying information about them, keeping in mind that people's residency at state hospitals is very often public information available through the census and vital records, and keeping in mind that some records from these institutions were never transferred to the Archives. This can be accomplished by creating a subcommittee of the Records Conservation Board consisting of the following stakeholders:
  - a. Stakeholders: Massachusetts Archives, Department of Mental Health, Department of Developmental Services, DPPC, Supervisor of Public Records, Records Conservation Board

- b. Time Frame: Immediate
  - c. Why is this important: As identified, processes are not consistent across agencies, largely due to a lack of coordination and communication.
- 5. **Make Head of Reference and Reference Archivists a proxy for DDS and DMH**, so that Archives may determine whether it is appropriate to release and make necessary redactions to any record currently in Archives' holdings from state institutions, in accordance with state law, as they do with other sensitive records such as prison records, eliminating duplicative and sometimes contradictory work for both the agencies and the archives.
  - a. Stakeholders: Governor, Secretary of Executive Office of Health and Human Services, the Secretary of State, and the Public Records Supervisor
  - b. Time Frame: Immediate
  - c. Why is this important: As identified, processes are not consistent across agencies, largely due to a lack of deference to the state's entity (Massachusetts Archives) for document retention, preservation, and access.
- 6. **Expand Archives' staffing**, adding an additional Reference Archives Assistant full-time position and Processing Archivist full time position, in order to deal with the influx of requests once these records are more accessible.
  - a. Stakeholders: Governor, Secretary of State, Massachusetts Legislature
  - b. Time Frame: In the next budget cycle
  - c. Why is this important: Given the volume of requests and significant expertise required to manage these collections, the Archives must have a dedicated position similar to other collection-specific positions like the Judicial Archivist.

## Category II: Recommendations for changes to laws around record access

- 1. **Pass the sunset law** currently before the legislature H.3335/S.2102, allowing all institutional records over 75 years of age to be made public with appropriate restrictions (see below) so that descendants, historians, and genealogists can better understand the history of Massachusetts and their own family histories.
  - a. Stakeholder: Massachusetts Legislature
  - b. Time Frame: Immediate
  - c. Why is this important: This step has been taken in dozens of other states. It will not impact documents about living individuals which are covered by the Health Insurance Portability and Accountability Act, which require that medical documents be sealed until 50 years after the death of an individual.
- 2. **Massachusetts Archives should immediately promulgate use restrictions** upon passage of the above-named legislation that prohibit the unchecked digitization and dissemination of institutional documents containing personal information akin to those used to encourage appropriate use of birth and death certificates by the Registry of Vital Statistics. Approval for such dissemination should be reviewed on a case-by-case basis by the Massachusetts Archives upon request.
  - a. Stakeholder: Massachusetts Archives

- b. Time Frame: Immediately following passage of H.3335/S.2102.
  - c. Why is this important: People should have access to records, but personal information, even regarding long-deceased individuals, should not be available for widespread dissemination without rules and procedures in place to prevent abuse.
- 3. **Modify MGL c. 4, section 7 (26) (c), MGL, c. 123, Section 36, and MGL, c. 123B, Section 17** in order to handle restricted medical records (records from within 50 years of the death of an individual) similarly to prison records: the researcher provides proof of the death of the person, and then the records will be open on a case by case basis, potentially with redactions for privacy, as determined by archivists. This will eliminate the need for a court order, which many researchers (often those who are researching personal family history) have reported they find cost prohibitive, time consuming, and confusing.
  - a. Stakeholder: Massachusetts Legislature
  - b. Time Frame: During the present session
  - c. Why this is important: The Massachusetts Archives must be empowered to make reasonable exceptions to access restrictions based on a demonstrated weighing of the public interest against (or for) the interest of the deceased without needing to rely on extensive legal evaluation or the existing Records Access Officers (RAOs) and policies of the state.

### Category III: Recommendations to improve access for former patients/residents or their families and researchers

- 1. **Post clear, easy-to-read, accessible, plain-language instruction for records access** that is uniform from agency to agency.
  - a. Stakeholders: Massachusetts Archives, Executive Office of Health and Human Services.
  - b. Time Frame: Immediate
  - c. Why is this important: The Commission has identified inaccessible language as a significant barrier to the public interest in accessing documents.
- 2. **Create an accurate, searchable, public-facing inventory of all existing institutional records.**
  - a. Stakeholders: Massachusetts Records Conservation Board in consultation with the subcommittee described above; funding to Mass Archives provided by governor and state legislature.
  - b. Time Frame: In the next budget cycle
  - c. Why is this important: People should be able to easily figure out which records exist so that they can go looking for ones important to them, and at the same time, they should be spared the process of looking for documents that will never be found.
- 3. **Train peer guides with disabilities** to be available upon request to accompany individuals with disabilities who have requested, received, and are preparing to review their records.
  - a. Stakeholders: Massachusetts Archives, Human rights officers of DMH and DDS, Disabled Persons Protection Commission; Funding from governor and Massachusetts legislature.
  - b. Time Frame: Financial support in the next budget cycle.
  - c. Why is this important: Going through these records can be confusing and traumatizing.

People do not always have someone they can rely on to go through these records with and this should be offered to them.

4. **Waive probate fees and create uniform probate filing requirements** written in plain language for individuals specifically seeking institutional records of deceased relatives who lived in institutions. Allow for plain language submissions of documents, limiting barriers of legal literacy and the financial burden of obtaining legal representation.
  - a. Stakeholders: Massachusetts Supreme Judicial Court with guidance from the Mental Health Legal Advisors Committee
  - b. Time Frame: Immediate
  - c. Why is this important: In informant interviews it has become clear that the probate process is financially prohibitive to descendants.
5. **Issue guidance clarifying that institutional cemetery burial records are vital records** like all other cemetery burial records in the Commonwealth, and must be made available on public request subject to redaction by the state archives should they contain any personal medical information that would not normally be contained on a vital record.
  - a. Stakeholders: Attorney General
  - b. Time Frame: Immediate
  - c. Why is this important: State agencies have long-denied public access to burial records for institutional cemeteries where disabled people are buried in nameless and unmarked graves, claiming that these death records are medical records because they show that people lived in institutions. This is an unwarranted and inappropriate interpretation of vital records, which often show that people died in hospitals or other medical settings.

#### CATEGORY IV: Recommendations to create a pathways for the return of institutional records to Massachusetts Archives.

1. **Temporary moratorium on prosecution for individuals who return institutional documents** in their possession, of a length determined by the Massachusetts Archives in consultation with the Attorney General.
  - a. Stakeholders: Attorney General for guidance and Massachusetts Archives for receipt.
  - b. Time Frame: Immediate
  - c. Why is this important: Many institutional documents appear to be in the hands of private individuals who have tried to protect them after finding them in abandoned facilities or had them in their possession from their time as employees of the state. They should not be punished for having preserved them, so long as they turn them over to the state.
2. **Issue a cease-and-desist order to online marketplaces** where institutional documents that were not initially promulgated for public consumption are sold. Pursue sellers of such materials and recover documents.
  - a. Stakeholders: Attorney General and Massachusetts Archives
  - b. Time Frame: Immediate
  - c. Why is this important: The commission has documented the commercial sale of institutional

documents and materials relating to specific individuals. It must stop.

3. **Issue a demand to private institutions, universities, non-profits, towns, cities, and any other organized and registered entities currently in possession of state institutional documents** from the Commonwealth of Massachusetts to return such documents immediately to the State Archives. Promulgate best practices that align with state policies for private institutions, universities, non-profits, towns, cities, and any other organized and registered entities that lawfully hold such documents. Require the aforementioned entities to provide an accurate inventory of their holdings to the Massachusetts Archives at all times.
  - a. Stakeholders: Attorney General and Massachusetts Archives
  - b. Time Frame: Immediate
  - c. Why is this important: Over time, non-state institutions have acquired institutional documents through a variety of means. When these documents pertain to the work of employees of the state or medical records regarding state institutional populations, they are more difficult for survivors, descendants, and scholars to locate, creating an undue burden for public access to documents that should be in the possession of the state. They should be recovered.

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# Members of the Special Commission on State Institutions

Member Name	Representation <i>(please note that some appointees are not employees of the organization or agency appearing alongside their name)</i>
Elise Aronne	Wrentham Developmental Center, Self-Advocate
Kate Benson, co-chair	Department of Mental Health, Self-Advocate
Sister Linda Bessom	Family Member of a Current Resident at the Hogan Regional Center
Reggie Clark	Massachusetts Advocates Standing Strong (MASS), Self-Advocate
Jim Cooney	Former employee of a state institutional facility (between 1970 and 2014)
Samuel Edwards	Archives Division in the Department of the State Secretary
Anne Fracht, co-chair	Department of Developmental Services, Self-Advocate
Alex Green, vice chair	The Arc of Massachusetts, Self-Advocate
Bill Henning	Centers for Independent Living
Andrew Levrault	Disabled Persons Protection Commission
Camille Karabaich	Massachusetts Office on Disability
Evelyn Mateo	Department of Mental Health, Self-Advocate
Lauri Medeiros	MassFamilies
Vesper Moore	Kiva Centers, Self-Advocate
Brenda Rankin	Wrentham Developmental Center, Self-Advocate