

March 27, 2024

**Via Email**

Honorable Governor Maura Healy  
Massachusetts State House  
24 Beacon St, Room 280  
Boston, MA 02133

Kate Walsh  
Secretary, Executive Office of Health & Human Services  
1 Ashburton Place  
Boston, MA 02108

Dear Governor Healy and Secretary Walsh:

The Special Commission on State Institutions has been charged with locating and reviewing existing records that are 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.

As the chairs of the Special Commission on State Institutions we are writing to you on behalf of the Special Commission, which voted in favor of this letter, to express our serious concerns for the circumstances and procedures that surround the closing of state-run institutions in Massachusetts. We request that there are actions taken to address the security of confidential documents of former residents found on the grounds of the Fernald Developmental Center in Waltham, as discussed in recent *Boston Globe* articles, and at other institutional sites and offices that have been previously closed or that will be closed in the future where personal records may exist.

This exposure of highly sensitive, personal information is a violation of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA), which prohibits disclosure of personal health and identifiable information. Not only is this an infringement of privacy, but it is also a violation of human dignity of former residents who have passed and for those that still live. In fact, The Department of Developmental Services provided a HIPAA Breach notification for the former Fernald Developmental Center on March 11, 2024.

Sadly, this is not the first time that confidential documents of former patients and residents have been mishandled during and after the closing of a state-run facility. For example:

- In 2000, the *Sun Chronicle* reported of the closed Foxboro State Hospital, “[a]bout the only documentation the Massachusetts Archives has of the former state-run psychiatric hospital is a series of annual reports and some general summaries of the facility.” A supervisor at the State Archives stated, “There are no case files for Foxboro ... we’ve seen similar situations for other facilities.” The article also speaks to the burdensome process for family members of former patients in obtaining records. “If a relative of a patient who was believed to be buried on the grounds of the former Foxboro State Hospital were to try to identify which numbered stone belonged to a family member, it would likely be an unattainable task”. Unfortunately, even if a ledger that matched patient names with numbers had been found, the search is still rather cumbersome due to the many restrictions that apply under state law since a lot of the information contains sensitive medical information. Oftentimes a family or estate must seek a court order to obtain access to the information.
- In 2014, Fox Undercover investigated this same topic and reported that confidential records were found in the Paul A Dever School and the Metropolitan State Hospital by “urban explorers.” One of the urban explorers interviewed said he had “found hundreds of private records in various state institutions,” records he says “definitely should have been moved. I have found plenty of information, personal information, medical records ...

I would have thought they would have at least been moved to an active facility, some secure facility." The urban explorer provided pictures of files full of records at several former state-run mental hospitals.

The Special Commission recognizes that the closure of any state-run facility is a complex undertaking that requires planning and coordinating between multiple state agencies and municipalities across the Commonwealth. Nevertheless, it is of utmost importance to always protect and respect the dignity of individuals who at one point in time received services at these facilities.


We appreciate the recent efforts of the Department of Developmental Services (DDS) to respond to the situation on the former Fernald grounds by securing documents in accessible buildings. We understand that some of the buildings are unsafe to enter due to their conditions and are encouraged to hear that a demolition company will be brought on to assist with the remaining records on the Fernald grounds. We respectfully request that any records that are found on site are collected, stored, and preserved at a secure location unless their condition requires their destruction due to their condition instead of being disposed of as part of the demolition waste.

The Special Commission on State Institution requests the Executive Office of Health and Human Services, the Department of Developmental Services, the Department of Mental Health (DMH), and the state's Division of Capital Asset Management and Maintenance (DCAMM) to address these ongoing issues by:

- a) Conducting an inventory of closed state institutions formerly operated by DDS and DMH to determine whether and where records are stored on the premises, including a sweep of all buildings and subterranean tunnel systems.
- b) Documenting what will be done to address any issues with record security at closed state institutions identified during the above process and the associated timelines.
- c) Developing an accessible, consistent, and clear process for former service recipients to request their own records, as well as for their immediate family members or estate to make such requests on their behalf, with the right safeguards to ensure family members or estate have the proper rights to the information.
- d) Developing a transparent process for the handling, storage, and retention of confidential records, as well as the terms under which disposal is permitted and how it is to be conducted, so that this type of situation does not arise again in the future.
- e) Creating an accounting of the records from closed institutions that may be stored at government offices or state-run facilities still in operation.

The Special Commission Members are willing to assist with anything that is within the Commission's capacity and purview. We hope that you will consider taking these steps to address these long-standing issues and respectfully request that you provide the Commission with a written preliminary response within 90 days of the date of this letter.

Respectfully submitted on behalf of the Special Commission of State Institutions.

  
Evelyn Mateo  
Co-Chair, Special Commission on State  
Institutions

  
Matthew Millett  
Co-Chair, Special Commission on State  
Institution

Cc:

Jane Ryder, Commissioner, Department of Developmental Services

Brooke Doyle, Commissioner, Department of Mental Health

Adam Baacke, Commissioner, Division of Capital Asset Management and Maintenance