A Report to the Massachusetts Special Commission on State Institutions

Plain Text Summary

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Introduction

This report was prepared by the Center for Developmental Disabilities Evaluation and Research (CDDER), a center within the Eunice Kennedy Shriver Center at UMass Chan Medical School, for the Special Commission on State Institutions. This Commission was created by the 2023 state budget. It has been asked "...to study and report on the history of state institutions for people with intellectual or developmental disabilities or mental health conditions in the commonwealth..." (Special Commission on State Institutions, 2022). The Commission is directed to:

- (i) review existing records in the held by the state about state institutions for people with intellectual or developmental disabilities or mental health conditions;
- look at whether records of people who lived at institutions are available to them an their families. If they are not available, look at what is getting in the way;
- (iii) look up and list records of burial locations for the people who died while in the care of state institutions;
- (iv) figure out if there may be unmarked graves at sites of former state institutions and where the graves may be; and
- (v) come up with a way to remember how the state treated people across history.

In 2023, the Commission selected CDDER to support its work. Since that time, CDDER has been gathering information through interviews, and review of articles and books about these institutions and Massachusetts history. CDDER has also reviewed Massachusetts state law with the help of lawyers. They have looked through hundreds of records. CDDER has put together this report of what it found for the Commission. This report was made to help the Commission think about what it would like to recommend.

This report begins with a timeline of events relevant to how the Commonwealth addressed people with mental health conditions and developmental disabilities who needed assistance. This timeline follows when institutions were created, and when and how the institutions started serving specific groups of people. It talks about when institutions closed. The timeline follows a changes in how the state and U.S. thought about and treated people with mental health conditions and developmental disabilities.

This report uses words that were used at in the past to describe people with mental health conditions and developmental disabilities. These words can be upsetting and hurtful. We kept these words in the report to show how people were labeled and the names they were called. The changes in these words show the changes in the way people with people with mental health conditions and developmental disabilities were valued over time. The words used were related to how people in institutions were treated, the rights they had, and how they were grouped. These words show how they were treated in life and in death.

This report then reviews the information that we have found so far about records with information about people who lived at state institutions. It also lists what we know about records that have been burned or lost. It also reviews the laws about getting records. It has information from people who have tried to get records about their family members who talk about how it went. The report then covers what is known about where the people died while living in institutions are buried, whether their graves can be named and how the bodies of people who died at institutions were handled over time. Lastly, the report covers how other states remember people who lived in institutions. Throughout these sections, there are things the Commission can think about doing as they pick what they want to do next.

Executive Summary in Plain Text

Historical Timeline

This report will look at the history of institutions in Massachusetts for people with mental health conditions and people with intellectual or developmental disabilities. We first look at how Massachusetts started to take care of different groups of people who needed help. We then look at how the way people were supported changed over time.

Public Welfare Laws and Programs

This timeline begins with how public help was given to people in Massachusetts, beginning with the Massachusetts Bay Colony. This Colony was where a group of people from English first lived in the 1600s before Massachusetts was a state. At first, people who needed help in these colonial times were all sent to places called places labeled as Poorhouses. They were called "the poor". Some laws were made and changed over time that controlled the help that was given to people who needed it. These laws changed over time because the towns found it hard to pay for the help that people needed.

To help limit how much money the towns had to pay, they tried to limit the number of people they needed to support. They sent bills to shipmasters and train operators that brought people to Massachusetts who needed support so they wouldn't bring as many of these people. They tried to push people out of their town by labeling them as "outsiders" so they would feel like they didn't belong. They tried to get money from the family members of the person who needed support. Over time, more laws were created that limited the rights of people who needed help and couldn't pay for it. Laws were made (starting in 1693) to let towns take property away from people who needed support and couldn't pay for it.

The towns started to make two groups of people who needed help. One group was of people who needed help and could work. The other group was of people who needed help and could not work. The laws started to change how they talked about people who could not work. Instead of talking about them as "the poor", they started calling them "inmates". An inmate is someone who lives with other people, but this name was used to mean a person who lives with other people not by their own choice. For example, people in jails are called "inmates". Early in the 1700s, people with who needed support and were "weak, sick, and unable to work" were also being put in jails more often. People lived in places that were in very bad shape, and they were not doing well in these Poorhouses and jails. People in the towns saw this and laws were created to make a group of people who would go check on how people in Poorhouses were doing. The people doing these checks wrote reports about what they found. They saw that people with mental health conditions and people with intellectual or developmental disabilities

were often not doing well. They said to lawmakers that people with people with mental health conditions or intellectual or developmental disabilities who needed help should live in places that just help these groups. They said people with mental health conditions or intellectual or developmental disabilities should not live in group houses mixed with all other people who need help and cannot pay for it. There also were not many rules about how people who needed help were to be treated around this time.

Lawmakers then started making places for just people with mental health conditions or an intellectual disability to live. They did this to try to make the places safer for these people to live. Housing was also created for people who needed help and could not pay for it but could work. The people who could work had to work to pay for their own services and raise money to support the places they were living and services they were given.

In 1788, Massachusetts changed from a group of towns to become a Commonwealth (like a state). After this, the towns were grouped into counties. The counties started to pay for help for those who needed it. Then, the state started paying for the help people needed. The state formed larger places for big groups of people who needed help to live together.

"Guardianship" was created by the court system in colonial Massachusetts. Under "guardianship" a court could pick someone to make important decisions for a person who could not care for themselves. Over time, the court was able to pick people to make decisions for the children of the people who needed help and could not care for themselves. Through the changes in the laws, people with serious mental health conditions or an intellectual disability lost their rights and property more and more. This caused people who needed care to be sent to these institutions whether they wanted to go or not. The people with disabilities became unable to make their own choice about whether to leave the institutions.

A Shift to State-based Care and Medical Care

The state-based institutions for care that were created started to include more medical services. They were called state hospitals. These hospitals were made to try to keep people with mental health conditions and intellectual disabilities out of jail. As medical training became better for doctors, they learned more about medicine. The doctors at the institutions tried to cure people with these conditions. Laws were made in the early 1800's to make sure people with disabilities were treated better when they were given help. While people with disabilities were treated better than they had been treated, the laws did not protect them fully. In the institutions, many people still had very bad housing and food. Many were also not treated well. Many were tied up or held down. Many were given medications to control them. Many were treated in very mean ways (abused) or not given the help they needed.

Attempts to Change How People Were Cared for in the Mid-1800s

Some leaders were trying to change how they cared for people who needed help. The changes they were trying to make were based on how they saw others caring for people in Europe. There the focus was on trying to help people who needed care get better and learn to help themselves. Institutions that cared for people were starting to split people into new groups. For those with mental health conditions they made a group of those that they thought could get better, and those that they did not think could get better. The doctors gave medical services to the people they thought they could cure. Doctors did not always know how to make people with mental health conditions better at this time and were trying to learn new ways to make people better. They tried things that did not work and they tried some very serious things that may have hurt people as they tried out new ways to try to cure them.

The new State Hospitals were built for people with serious mental health conditions. They had areas with medical equipment, and places where people who needed help lived. The living areas had cells like a jail with bars and locks on the doors. New rules were created about forcing people with mental health conditions to go to live at these State Hospitals. There were also new rules controlling if and when people could leave the State Hospitals in the 1800's. Rules were also made about whether people could be punished for things they did, and when people outside the State Hospitals had to visit to makes sure the buildings and people were safe. Even though these were called "hospitals" the people there weren't called patients; they were called "inmates" like people in jail because they were not allowed to leave if they wanted to.

Later, different institutions were formed for people with an intellectual or developmental disability. People with these disabilities were moved from Poorhouses and State Hospitals into the new institutions. New ways of caring for children who needed help were also made. Children who were poor were sent to work for families that were not their own. These families were expected to care for the children who worked for them. There were also places that were trying to see if children with an intellectual or developmental disability could be taught new things. Special schools, like children who are blind, and one for children with an intellectual or developmental disabilities. At this time, children with these disabilities were not able to attend local schools.

In the early and mid-1800s in the U.S., the ways and places people worked were changing. New machines were being invented that made things faster, like making cloth. More people moved away from farms to cities to work at new factories that used these machines. New "Reform" schools were made. Children were sent to live at these schools for reasons like being poor, not listening to their parents, or who others broke some small laws like stealing small items or not attending regular school enough. The point of the schools was to teach these children to follow the rules and learn job skills. While children with disabilities were frequently sent to Reform schools, the schools had a hard time working with these children. As more people moved to cities and started living more closely to each other, fears grew about people with mental health

conditions. For these reasons, state leaders made special places ("asylums") to send people with serious mental health conditions away from others in the cities. Between 1870-1930 the state quickly built 10 new institutions for people considered to be very ill from their mental health condition and "training schools" for people with intellectual or developmental disabilities. The last of these new institutions to be built was Metropolitan State Hospital for people with mental health conditions in 1930.

Moving people with disabilities away from everyone else connected with some ideas that a group of people had about how to make better races of people. These ideas were spreading during this time. People who believed we should make a better race of people wanted to control who could have children. They did not think that people with disabilities were part of this better race. They also did not think people with certain medical conditions, or certain hair colors, skin colors, and other factors should be included. They thought the world would be better if people like this were removed from the community and were not allowed to have children. One of these state institutions, Monson State Hospital, was led by someone who believed in these ideas. He gave money to support the study of the people who lived there and their parents and grandparents. An event was held on the grounds of Monson where many other people who shared these ideas came to talk about them and make plans. They also performed surgery on people to make sure they could not have children because they thought they were not good enough, even though doing this was against the law.

Growing Civil Rights and a Call for More Community-Based Care

In the 1920's, there were calls for institutions to be closed and made smaller. Instead, they thought people with mental health conditions and intellectual disability should be supported in the community. They thought people with intellectual disabilities should be taught new things. The institutions in the state had become very, very overcrowded and got very little money from the state to pay for caring for all of the people there. During this time, there were big changes in the U.S. laws. A new program called Social Security Act (1935) was started to give money to people with disabilities to help them care for themselves or pay others to help them. Groups of people formed who were fighting to help people with mental health conditions and groups fighting to help people with intellectual disabilities. The groups fighting for changes were unhappy with how these people were being treated in institutions. The newspapers and filmmakers were also sharing information about what was happening in these institutions, including very bad and very serious things happening to people with disabilities. The people fighting for change used this information to get leaders to understand the need for change. In the 1960's, President Kennedy's called for change. States including Massachusetts started to move people out of institutions and close some of them. They started offering more services in the community. Lawmakers passed new laws that gave people with disabilities more rights and protections against being treated unfairly. New programs were created to pay for medical services and other types of services for people who were poor, older, or who had disabilities.

Support for Services in the Community Came from new Laws and Lawsuits

In the 1970's, lawsuits were filed in Massachusetts about how large groups of people with intellectual disabilities were treated at the state institutions. Lawyers told the court that the people living at institutions had rights, and that forcing people to live at the institutions and be treated like that took away their rights. The court agreed. The homes were created in Massachusetts that had staff to support people with intellectual disabilities to live in the community. During the 1970's, new centers called "Independent Living Centers" were being created to help people with disabilities to support themselves and live on their own where they wanted to. The U.S. also made new laws and courts agreed that people with mental health conditions can't be forced to go living in an institutions like State Hospitals if they were not a threat. The laws also said that people with intellectual disabilities must get the help they need in the least controlling type of place possible. Because of these changes, Leaders in Massachusetts started to close institutions for people with mental health conditions and for people with intellectual disabilities. The last state mental health hospital, Metropolitan State Hospital, closed in 1992.

Current Day

Now, two institutions are open in Massachusetts for people with intellectual and developmental disabilities, Wrentham and Hogan Developmental Centers. There is one mental health state hospital, Bridgewater State Hospital, where men are locked up. These are men with mental health conditions that have been sent to live there by a court, and men who are charged with a crime waiting to go to court and for a mental health doctor to meet with them. There is also Tewksbury Hospital that was once the site of a Poorhouse. There are now groups of buildings next to each other. People with many different types of needs get help there. In one set of buildings, about 150 men with serious mental health conditions live and get help there in locked buildings. There are also two locked sections for teenagers who need help with their mental health and other types of needs. There are also about 300 people living there who are getting help to stop using things like drugs and alcohol.

Executive Summary: Records & Records Access

As people mental health conditions or developmental disabilities got help from public support systems, different types of records were made.

The paperwork about people who lived in Massachusetts state institutions for people with mental health conditions and developmental disabilities has changed a lot over time. As time went on, the records had more and more details in them. What was included in the paperwork was related to the reason the records were made, and what they were required to do at the time. There were laws and rules created about what must be put in the records of the institutions and these changed over time. Rules were made about writing down what happened to people as people visiting the institutions found that care was not always good for people

with disabilities. As more doctors became involved in the care, the records had more healthrelated information. When the institutions did more to try to teach people with developmental disabilities, the records had more information about how people were learning and the results of tests. As other processionals like Social Workers started working in institutions, there were more details about people's families and relationships and details of their different types of support needs.

At first, records at institutions were used to track who came to the institution and why people thought they needed help. These records were sent to a central group in the state called the Board of State Charities. These early records were grouped by whether people got support from the state or groups funded by others. Later, records were put in order of a number assigned to each person. These records were used to track the patients and run the institution.

Early institutions collected information to show they were worth the state sending them money. The leaders began sending the state reports about what they were doing. Sometimes these reports had a lot of information about the people they were helping. This could include their name, and how old they were. The reports also had information about why people needed help and where they came from. Sometimes the had information about who paid for the help to the person and if they died or moved. The records did not have information about the care given or how people were treated.

The quality of the records was not very good. They were sometimes in messy handwriting that people could not read.

State Schools for the "Disabled"

Early school files included information about living at the school. Records had info about peoples medical conditions, who their parents were and where they were born. The had info on the person's family and some tests about how well the people did certain things like solving puzzles. Records could include letters with parents and other caretakers. Some records included following who left and when they left, or if they died.

Once-a-year reports from the schools Massachusetts State Schools made a summary of the information they collected about patients and what the school did that year. Reports had information about how much money they spent, how many people came or left and the health of the people who lived there.

Later pictures of people were added to their records. More information from doctors was added as they did more medical test with people there. Some records had information about people's teeth, how much they weighed and what they ate. Tests of their genes were added to some people's records when genetic tests were available.

The main types of records that were kept across time include:

- Records about people asking for services, people entering services or leaving services
- Court records and records from doctors about why people should receive services
- Waiting lists
- Listings about who was living at the institution
- Files about each person that lived there
- Records about things that happened to people while they lived there. These were things like going to the hospital, being held or tied up, when got hurt by staff or other people living there, and when people did not get the help they needed from staff.
- Reports once a year about the money the institution got and spent, what they did with residents and summaries of information they followed that year
- Records about where people were buried and studies of their bodies
- Reports from people whose job it was to make sure the institution was doing what it was supposed to do

Where to Find Records

Some of the records from institutions are available on the internet. Some are held by a group in the state that takes care of old state records (the Archives). Some state agencies still have their old records. Some records are in university libraries, some are in private collections. Some records burned in fires at institutions or were lost. Some records were not locked up when they should have been and people who went to closed institutions could get them. Some records that were not locked up were stolen, and some were sold to other people online.

How records were kept also changed over time. The laws about which records must be kept by the state changed over time. Also laws about how people can access these records changed over time. Today, the laws say that regular records about people from institutions only need to be kept for 20 years.

The records that were kept from state institutions are stored in different places. Sometimes we have a lot of info about what records are at a certain place. Sometimes we do not know very much about what they have. Also, the records may be in good shape or they may be falling apart. The rules about getting these records and how you do that depend on who has the records and what is in them.

Lawyers at Harvard Law School helped us look at the laws about records at state institutions. They found that there were only a few laws that talk about these records. There are also a few court cases. They suggested the Commission could ask for changes to those laws based on changes that other states have made to their laws.

People who have tried to get records of their family members say it is hard, costs money and is confusing. People who want their family's records often need to pay a lawyer for help. They may need to go to court to prove they are the person's family and have a right to see the record. People found it frustrating that agencies say the law says they cannot tell the family if

they have a record until they go to court and pay fees. If they do get records, they feel like info is missing or they did not get the full record.

Actions for the Commission to think about doing:

- Asking for more information about records that the Department of Development Services and the Department of Mental Health has.
- Ask state agencies to put steps together for when they close an institution or state office to keep the records safe.
- Ask for lists of the records that state agencies have asked to get rid of over time from the MA State Archives.
- Ask the person who looks after all state records to look at the read the laws and make a decision about which laws relate to records from institutions.
- Share ideas for how to change the rules about how long state records are kept
- Ask for changes in laws about access to records of people who lived at institutions by family members.
- Share ideas for how to make it easier for family members to get records. Share ideas for how to help families know what records a state agency does have and which they do not before going to court.
- Think about asking for changes in how long families and other people have to wait to get records from institutions.
- Share ideas or ask for rules about how people can get state records that are not kept by the state.

Burials and Places Where People are Buried

When someone died in a Massachusetts state institution and had no family or money for a proper burial, the institution usually took care of it. They often buried the person on the grounds of the facility.

Institutional Burial Practices

Burial practices at different institutions were almost the same, focusing on simplicity, hiding people's names, and no special events at their death. Graves were often marked only with numbers or basic symbols. For example, MetFern Cemetery, linked to the Walter E. Fernald School and Metropolitan State Hospital, used a letter ("C" or "P") to show whether the person was Catholic or Protestant, followed by a number. This method did not list who was buried at

each grave, likely because there was shame about living at an institution. Some believe this was done to protect families from shame if a relative died in an institution.

Reports from some institutions like Taunton State Hospital show that inmates built simple wooden boxes and sewed burial clothes like sheets and nightdresses. Other inmates sometimes took part in the burials, offering prayers or songs. At places like Belchertown State School, inmates also dug the graves where people were buried. There was little celebration of life, and residents were often just told that someone had "left" when they had died.

Having the patients make boxes to put bodies in and digging graves highlights how they were treated with little respect. Over time, burial practices changed because of new laws and financial struggles like the Great Depression and disease. For example, some institutions like Worcester State Hospital and Medfield Insane Asylum had to create new cemeteries on the institution's property after a lot of people got the flu in the early 1900's. Foxborough State Hospital had to create a new cemetery during the Great Depression because families did not have enough money to bury their family member in a private cemetery plot.

Death and Burial Records

The laws and processes for death registration, burial permits, and certificates in Massachusetts were created to help keep accurate health and historical records. In 1842, Massachusetts required towns to keep records of births, marriages, and deaths and send them to the state every year. At first, the system was not organized well, and there were gaps in the data, especially for deaths in institutions like hospitals or prisons. A report in 1842 recommended changes, such as using standard forms, requiring informants to report deaths, and creating burial permits and death certificates.

By 1860, these changes became law, and undertakers had to get burial permits from town clerks. Death records also had to include more details, like the cause of death. Over time, more rules were added, including a requirement in the early 1900s for undertakers to file death certificates with local health boards before getting burial permits. However, hospitals and institutions didn't always have to file full death certificates, which led to missing information.

In 1935, Massachusetts made the person's hometown responsible for death records, even if the person died in an institution. This was done to fix the gaps in recordkeeping. The system continued to improve, and in 1964, the responsibility for vital records was moved to the Commissioner of Public Health.

Unmarked Graves

Unmarked graves, especially in old cemeteries linked to state institutions, are hard to identify and protect. As institutions like hospitals and schools for the disabled aged, many graves were marked with temporary or weak markers, or sometimes not marked at all. Over time, these markers may have disappeared or been moved, especially in cemeteries near developing areas, making it hard to find and recognize the graves. To address this, careful research and tools like Ground Penetrating Radar (GPR) are used to locate and protect these sites.

Massachusetts has laws to help protect burial grounds and unmarked graves. Important laws include:

- Keeps burial grounds safe that are more than 100 years old.
- People must immediately tell the state if human remains are found.
- Allows towns to take care of old burial sites to ensure they are protected.

There are examples in Massachusetts that show how tricky it can be to deal with unmarked graves. For instance, the old State Reform School for Boys in Westborough, which later became the Westborough Insane Hospital, may have unmarked graves of former inmates buried on its grounds. If these graves are found, they must be handled according to the law, especially because the site is protected land. Similarly, the Northampton State Hospital burial ground, used from 1858 to 1921, has 181 confirmed burials, but many records were lost, and the site no longer looks like a cemetery.

In 1981, human remains were found at Bridgewater State Hospital, but there were no official records of a cemetery there, so it was unclear how many graves were actually on the site. In 2010, a historian found a cluster of stones at Foxborough State Hospital, raising questions about unmarked graves, but there is little documentation to identify who is buried there.

Studies of People's Bodies for Science

In 1921, Massachusetts passed a law (Chapter 113) that required state institutions to send bodies of people who had died at institutions to medical schools if their family did not come get them. The law stated that the body had to be sent within three days unless family or friends claimed it. The body also had to be kept for 14 days to allow time for identification and to ensure a proper burial if no one came forward.

This practice continued into the 1900s, but medical schools no longer asked for bodies as much. Newer ways of getting bodes cadavers took its place. Today, the law is mostly seen as a part of history, reflecting past ways of training future doctors.

During the early 1900s, some institutions, like the Danvers Insane Hospital, wanted to change the law to allow autopsies without the family saying it is okay to do. Pathologists argued this would make it easier to perform autopsies and help advance medical learning. These efforts were supported by state officials, such as the Commissioner of the Department of Mental Diseases, who encouraged hospitals to give more bodies to medical schools. While these practices helped in medical research, they also raised serious concerns about what is right to do, especially because the people who died did not say it was ok to study their body. People were afraid they were not being respected after they died. The burial practices for people who died at Massachusetts institutions show how laws, money and social rules shaped how they were treated. Often there was more respect for the need of the institution than the person who died. Graves were marked simply or not at all, and patients sometimes helped with funerals. These practices highlight the exploitation and neglect of these individuals. Although recordkeeping improved over time, many graves remained unmarked, and identities were lost. These past practices still raise important questions about how vulnerable people were treated and the ethics of state policies.

Actions for the Commission to think about doing:

- Ask lawmakers to take away the law which makes state institutions to give bodies of people who die there to medical schools if their family does not claim them
- Write down steps for local historical and conservation groups on what to do if they have possible unmarked graves in their town.
- Support fixing up cemeteries to keep them in good shape and safe.
- Make public lists of those buried in cemeteries where only numbers were used, so their identities can be listed.
- Install better signs at burial locations to explain the history and what's important to know about the site.
- Address the conditions at "The Pines" cemetery in Tewksbury to ensure its preservation and proper care.
- Close the pathway to possibly move the graves at Glavin to protect them.
- Conduct research on areas where unmarked graves may exist to better understand and protect these locations.

Framework for Remembering Massachusetts' State-Run Institutions

The Special Commission on State Institutions will be working on a plan to publicly recognize the state's role in running institutions for people with intellectual disabilities and mental health conditions. This includes suggesting ways to remember the past and educate the public. The goal is to acknowledge the painful history of these institutions while celebrating the strength of the people who lived in them. The plan will also highlight efforts to support people with disabilities living independently in society today.

The Framework for Remembrance Workgroup has learned from other memorial projects in different states. These projects help preserve the past while promoting fairness and belonging of all people. Some examples include:

- Belchertown State School Friends Association: This group is creating a museum and memorial to educate people about the history of special education, institutional care, and disability rights.
- MetFern Cemetery Project: This project, started in 2018, focuses on honoring people buried at MetFern Cemetery by involving local high school students in the restoration and research.
- Danvers State Memorial Committee: This group has worked to restore the cemetery at Danvers State Hospital and made sure some of the property on the old campus would be used for housing people with mental health needs.
- California Memorial Project (CMP): This project restores cemeteries and holds remembrance events each year to keep the history of state institutions transparent.
- Willowbrook Mile Memorial Walking Trail: Located at the former Willowbrook State School in New York, this trail tells the history of what happened at the school through accessible interpretive stops and highlights human rights and advocacy.

These projects focus on making sure that the memorials are accessible to everyone, including people with disabilities. For example, the Willowbrook Mile Memorial made sure the paths were wheelchair-friendly and provided signs in braille and large print.

Important lessons from these projects include:

- Early Engagement: Involving former patients, their families, and local groups early on is important for making sure the memorial reflects the community's history and needs.
- Clear Purpose and Shared Goals: Keeping the group focused on a common goal helps drive progress.
- Ongoing Involvement: Activities like public hearings and rallies keep the issue visible and can influence decision-makers.
- Effective Communication: A strong message is necessary to gain support from the public and policymakers.
- Planning and Risk Management: Good planning, including budgeting and legal matters, is essential to success. Finding funding from different sources is also important.

The memorial must be a respectful space that helps with healing while honoring the dignity of everyone involved. The Framework for Remembrance is a chance to reflect on past wrongs and work toward a more inclusive future. By learning from history and promoting social justice, this

initiative can educate future generations and ensure that society embraces everyone with dignity and respect.



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