

Chapter 5: Poor Houses, Institutions, Eugenics, and Sterilization Laws

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This is a draft chapter that will be ultimately included in a coursebook that I am writing about the systems and laws that exist to support people with DD. This intellectual property belongs to Nancy Cronin and can be used with permission and correct citation.

<https://shadowsofpineland.org/>

<https://www.youtube.com/watch?v=BxSBxv1tTlo>

https://www.youtube.com/watch?v=6NYB_C6tVnA&t=84s

Attention

Learning Outcomes

- Understand the history of how people with disabilities in Maine and around the US were treated.
- Identify Maine History related to General Assistance, Town Farms, and Pineland History.
- Develop an understanding about past trauma for people today who experienced living in institutional models.
- Understand, on a basic level, the concept of trauma informed practice.
- Discuss the risks and benefits regarding genetic testing in light of disability
- Discuss the patterns of how service policy influenced people with disabilities experiences and quality of life.

Teaching

Trauma Informed Care

In this course I write about difficult topics. It is hard to hear about things that today in Maine most of us couldn't imagine. But those who are still alive remember, and lived in Maine's Institutions, including Pineland. Pineland Institution closed in 1996, well within many of our lifespans. Some of the more difficult things that I talk about were done to people alive today. These very people might become your clients. It is important to recognize that the people you work with may have experienced trauma(s). This is true regardless of their age and whether they experienced institutionalization. As professionals it is important to work from a trauma-informed way. This method does not aim to treat symptoms or the core issue, but instead to ensure that the help you are trying to provide is done in a way that the person can access and to prevent re-traumatization. For people with Developmental Disabilities that includes understanding the history of how people were treated. For more information review:

<https://socialwork.buffalo.edu/soci-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html>

Why learn the history?

For history not to repeat you need to know it! We need to know how we got where we are in today's system of care in order to do better tomorrow. That is the point, we want the future to be better than the past. Unfortunately, humans sometimes get nostalgic about the past, thinking it was better and this tendency can, at times, create environments where history can be repeated.

The history about how most of the United States, and all of Maine structures helping those without the ability to help themselves was locally modeled after England's Paupers law. People with disabilities who could not care for themselves independently or earn enough money to care for themselves were cared for by their families. If an individual didn't have a family willing or able to care for them and if the individual had no resources to hire somebody so that they could live independently, then the town was responsible to provide resources for the care of the person. Individuals who may have fallen into this group were not just people with disabilities but also widows, orphans, individuals with substance abuse disorders, Veterans, and the elderly.

Today (and in the yesteryears) Maine's towns and cities have a governance structure where the residents vote for City Counselors or Selectman. Upon election the official takes an oath to work for the benefit of the town and take responsibility as an overseer of the poor. I was voted in as a Selectman for the little rural town where I live. I will never forget that oath where I swore to be an Overseer of the Poor. As a Selectman I participated in the towns budget, signed off on the towns bills, made proposals for town meeting regarding how the land would be used, oversaw general assistance, taxation, and once voted to pay for a pauper's funeral. The year was around 2018. A pauper's funeral (which is still what it is called) is when an individual in town dies and nobody has the responsibility or money to bury them. The responsibility of handling that is the local elected officials, specifically, the Overseers of the Poor.

Programs like Social Security (which was signed into law in 1935), Medicare, and Medicaid (which were signed into law in the 1960s) partially took the weight off the town as these programs provided some Federal money and healthcare for people in poverty. We will talk more about these programs in subsequent chapters, but until the early 1900s it was the towns responsibility to care for people who didn't have the means and support to care for themselves. There were a couple of ways that towns did so. The most dramatic, and in my opinion most humiliating, was the annual auction at the town meeting. An individual who was an orphan, person with a disability, widow, elderly, etc. would be forced to stand in front of the assembly at the town meeting. Town residents who thought that they could support an additional person in their household would assess how much labor the person could provide. Then they would suggest a sum to the town to compensate for additional care that the individual might need. The individual in need went to the lowest bidder. I can imagine an older child being a more valuable commodity for their ability to help on the family farm or with the family business so the resident might ask for a small fee to care for the child. I can also imagine an elderly person who was quite frail or an individual with disability who needed a lot of support not being as valuable a commodity, so the resident would ask for a much higher rate to care for the person in need.

But what happened when there were not enough town residents willing to take in these people who needed help? The town would either provide funding to a local community who had developed a Town Farm or fund a Town Farm to be developed in their own community.

Town Farms and Town Farm Road

<https://www.sunjournal.com/2021/12/09/overseers-of-the-poor-life-on-the-farm/>

Google “Town Farm Road” in Maine and you will likely find quite a few houses for sale on streets named “Town Farm Road.” Every community either had a Town Farm, located on Town Farm Road or contracted with a neighboring community to send their poor to the neighboring Town Farm on their Town Farm Road. The exception to the Town Farm was when the town had a jail which might have had an area specifically reserved for these people. Wiscasset Old Jail is one example of such an arrangement. In 1810 the town funded a third floor to the jail where the area’s poor could reside. That building is still standing, and you can go and take tours of the jail and the third floor.

<https://www.lincolncountyhistory.org/visit/museums/wiscasset-old-jail/establishing-the-jail/>

For communities that opted for the Town Farm route they would hire a custodian to run the farm with the assumption that the custodian’s wife would care for the residents. He and his wife would run the farm and put the resident to work at whatever level that person could contribute. The custodian would be responsible for providing for the person’s needs. The idea was that the Farm would pay for itself with its own produce and goods. Rarely, but occasionally, that happened. More commonly the Farm operated at a loss and the Overseers of the Poor would need to provide additional tax dollars. The custodian and his wife would usually only stay for a year or two. The work was hard. There were many abuses that could occur. Think about the range of people being forced to live there. The home included at any given time a combination of elderly, widowed, orphaned, poor, homeless, sick individuals with contagious diseases, disabilities, mental health issues, and substance disorders. There were no limits on the number of people in the house and overcrowding could occur. I imagine life on the Town Farm would be difficult not only for those who ran the home, but the people forced to live all together there.

For the Selectmen and City Counselors charged with Overseeing Town Farms there were frequent debates over costs.

Dorothea Dix

Dorothea Dix was born in Hampden Maine in 1802. Dix moved to Worcester Massachusetts as a child and was raised partly by her wealthy grandmother. When she was 14 she became a teacher to some of the poorer children of the city. She began taking note of poor houses and treatment of people with mental illness. She was distressed at the conditions of the poor houses which were the only alternative to being placed in prisons.

Hampden had its own Town Farm Road although I couldn’t find any documentation of Dix visiting the Town Farm in Hampden Maine but I did find this interesting account from a visit by Dorothea Dix to a Town Farm in Rhode Island.

<https://littlecompton.org/historical-resources/little-compton-womens-history-project/deborah-pearce-hilliard-brownell/>

Dorothea Dix advocated tirelessly for the better treatment of people who had mental illness. Her work began in Massachusetts, but the system of care in that State mirrored the care in Maine. Dix advocated for State funded and run hospitals. Her work directly began the rise of institutions. That said, at the time, the institutions were considered sanctuaries from the cruel treatment that many people with disabilities experienced in the Town Farms and prisons.

This is an excellent 3 minute summary of Dorothea Dix's work.

<https://www.youtube.com/watch?v=FmkX9s9EH1Q>

Two Roads Diverge in the Fourteenth Century: Idiocy and Lunacy

Institutions arose in Maine in the early 1800s. The field of psychology hadn't yet truly been born. Modern medicine was also at its infancy. Since the 1400s, both mental illness and intellectual disabilities were known to be related to the brain. So why two different systemic pathways developed for those with intellectual disabilities as opposed to those with mental illness? After some research I couldn't find a clear answer, but I did learn enough to develop a theory that I will share with you.

Like the term "Idiot," the word "Lunatic" is very old, in fact "Lunatic" is a little older than the word "Idiot." Lunacy comes from the period of the 1300s from observations that people can go through "spells" of mental illness for a period of time and then behave "normally." The term "Idiocy," or "Idiot," comes from the 1400s to define people considered to have lower intelligence. These two terms appear to be constant through the ages. In the 1500s "Insanity" came to be a term in addition to "lunacy." The root word of "lunacy" is "luna," from the word "lunar," meaning moon. "Lunacy" references that people can have periods of "madness" which may change in degree or for periods of time stop altogether. "Insanity" references a more constant state of mental illness.

Over time "idiocy" and "insanity" continued to be thought of as two separate *types* of disorders. The words used in the texts describe "insanity" as *treatable* while that is not the impression when I read the the word "idiot" which describes those people as potentially "trainable." Today we know that nothing is that simple. Providing treatment and support for people who have neurological or/and mental illness needs to be individualized, and the best practice is to believe that the state of people's lives can improve with help. However, that is a modern interpretation.

The idea that some people may be mentally ill for a time as opposed to permanently disabled is an important distinction. The fields of mental illness and developmental disability split in the 1700s and have really remained separate to this day. Developmental Disability slowly evolved to include intellectual disability and other disabilities present at birth such as cerebral palsy and even epilepsy. During the age of institutions people were split into two different systems depending on the two categories. The system sent people to the mental health institutions when there was a chance of recovery or improvement. People who were sent to institutions for people who had Developmental Disabilities were not expected to every get better but instead learn skills within their capabilities.

Institutions

Augusta Mental Health Institution and Bangor Mental Health Institution

In the 1830s Dorothea Dix frequently visited Augusta Maine to consult on the effort to build the Maine Insane Hospital, later called Augusta Mental Health Institute and locally called (AMHI). In 1901 the State opened Bangor Mental Health Institute (BMHI), locally called (BaMHI). In 2005 BMHI changed its name to Dorothea Dix Psychiatric Center. AMHI closed in 2004 replaced with the Riverview Psychiatric Center on the same campus. Both Dorothea Dix and Riverview are run by the State of Maine today.

Below is a 18 minute documentary that provides a brief history of the buildings, the people who resided there, why it closed, and the current status of the campus today.

https://www.youtube.com/watch?v=40qCO_jrO7g

Pineland Hospital and Training Center (Pineland)

In 1903 Maine's legislature began studying what to do with people who, today, we would call having Developmental Disabilities. While individuals deemed as mentally ill may have "escaped" the Town Farm for the Insane Asylum many others remained in the Town Farm. In 1905 the legislature published a report that said "After full investigation of this subject, we most earnestly recommend to the Legislature of Maine, that humanity demands at our hands the location of such a home for this unfortunate class: that economy and the protection of society demand it." In 1908 the Maine Home for the Feeble Minded opened. At first the institution was well funded but over the upcoming decades periods of overcrowding at the Maine Home for the Feeble Minded and lack of direct care staff eroded Dorothea Dix's version of a safe haven and instead became a thing of neglect. In 1957 the name was changed to be "Pineland Hospital and Training Center." This week's assignment will be to review the website shadowsofpineland.org and learn a bit more about the history, and the lawsuits that ultimately closed Pineland with the last resident moving to a group home in 1996.

For some additional history about institutions and State Hospitals from a slightly different point of view take a look at this well-made documentary <https://www.youtube.com/watch?v=wmAqPe65M5c>

Briefly, what about the other people who were at the Town Farms? Foster Care, Orphanages and Nursing Homes

Individuals with mental illness went to psychiatric hospitals like AMHI. Individuals with Developmental Disabilities, Physical Disabilities, or Economic Disabilities who didn't have families who would care for them went to Pineland. But what about the others who used to reside at the Town Farm? How about the children and the elderly?

At the same time that Institutions were being funded, orphanages were being opened. These institutions did not just accept children without any parent, it also sometimes accepted children who only had Mothers. Mothers were frequently required to reform any undesirable qualities that the funders of the asylum deemed appropriate. Children were to be cared for and educated so that they could earn a living upon adulthood. See here for more Maine history: <http://www.maineorphans.info/>

For the elderly, over time, the Town Farm structure shifted into the State Nursing Home Structure.

Eugenics

Last chapter I introduced social Darwinism. In the Attention Section of this chapter, I introduced Eugenics. Eugenics was a pseudo-science prevalent in the late 1800s to early 1900s. It was a pseudo-science, not a genuine science. But I am not convinced that the people of the day didn't think that it was a real science. Eugenics mixed the science of animal husbandry (heredity science) with genetics. The thought was that if people could modify animals based on breeding combined with Darwin's theory of the use of natural selection to create better species why couldn't we modify human's breeding to create a better human? This is, after all, what Mendel found with pea-plants and others found breeding horses and dogs. This might sound shocking, but the concept of making better humans is not farfetched as we move along the field of genetics and gene modification.

The flaw of the Eugenics theory which makes it a pseudo-science was the assumption that heredity, in and of itself, was the only factor to the outcome of a human's offspring. Today we know that genetics is far more complicated, and the field has a general respect for the impact of the environment in which people are raised. At the time, however, when Eugenics was considered evidence-based there was the belief that all kinds of things could be passed down to offspring, for example, sexual behavior, morality, substance use, and disabilities. Science evolves based on new evidence over time. The theories surrounding Eugenics have been proven untrue and replaced by the science of Genetics.

None the less, policies were developed based on the field of Eugenics in the early 1900s and some of those policies are still in the books today. It was politically and medically believed that the best way to prevent many of societal issues such as poverty, prostitution, drug use, and people with disabilities was to remove these people from society. With the signature from a physician, an individual could be committed to Pineland due to feeble-mindedness or moral feeble-mindedness. The people committed (mostly for life) to Pineland had Developmental Disabilities, or had physical disabilities, or had disabilities that were not well understood like dyslexia and epilepsy, or were poor, or were anything that didn't fit well enough for them to be committed to a psychiatric facility. The societal value of these people under the umbrella of Eugenics was very low.

People who were committed to live in Pineland were separated by gender and by their ability. It was important that the residents were not allowed to reproduce. Further, it was important for these individuals, according to Eugenics practices, to be separated from the rest of society.

Regardless of age, they were called boys and girls, perpetuating the myth that individuals with Developmental Disabilities don't grow up. Those with greater abilities were left to care for those who had less abilities. Many staff cared greatly for residents as you will see when you examine the shadowsofpineland website, but some staff were physically, sexually, and verbally abusive. Those with greater abilities were also largely kind, but some were physically, sexually, and verbally abusive as well. Throughout much of the early to middle twentieth century many medical doctors didn't think people with Developmental Disabilities experienced pain like everyone else. Healthcare was often different. Behavior management within the institution was sometimes very cruel. I know of more than one person who resided in Pineland who no longer have teeth. This is not because of poor oral hygiene but because if they bit somebody in defense or otherwise, they would have their teeth removed as punishment.

<https://everybody.si.edu/citizens/eugenics>

Sterilizations

Chapter 275.

AN ACT to Regulate the Sterilization of Inmates of Institutions.

Be it enacted by the People of the State of Maine, as follows:

Sec. 1. Provisions for recommendation for sterilization in certain cases. Whenever it appears to the medical staff or institution physician of any institution in this state which has the care or custody of insane or feeble-minded persons that any inmate under the care or custody of such institution would be likely, if released without sterilization, to produce a child or children who by reason of inheritance would have a tendency to serious mental disease or mental deficiency, said medical staff or institution physician shall submit to the governing board of such institution a recommendation that a surgical operation be performed upon said patient for the prevention of parenthood.

Eugenics led countries like Nazi Germany to kill people who were considered “undesirable.” The United States chose a different strategy to ensure that people who were considered “undesirable” did not reproduce. Specifically men and women could endure surgery, without consent, that prevented them from reproducing. The above picture is from Maine Public Law Chapter 275 which was passed in 1931. In the next decades, at least 326 people, the majority of whom were women, were sterilized in institutions across the state, 189 of them at Pineland.

I know more than one individual, alive today, who woke up after surgery and later learned that the ability to reproduce was removed from them. The practice of sterilization is rarely used today but it still on the books.

In 1982 a law was passed in Maine that ensured at least some measure of Due Process for people who are about to be Sterilized. You can find the statute here. <https://legislature.maine.gov/statutes/34-B/title34-Bch7sec0.html> It requires that before sterilization is done there must be consent (permission) given from the individual. If the individual is under 18, under guardianship, residing in a State Institution, or refused to give the physician consent there must be a hearing and the determination of sterilization must be made through the courts. Maine doesn't collect data on sterilization because of privacy laws so I am unclear how frequently this may happen, if at all. But the law still exists and in my opinion the law needs to be reviewed for repeal, or at minimum, public reconsideration.

There have been a couple high-profile cases regarding sterilization in most recent history regarding people with Developmental Disabilities. One that comes immediately to mind is of a girl just reaching puberty. Her parents wanted the puberty to stop. They wanted her to have a hysterectomy (which is essentially what sterilization for women is) and remove the girls breast buds. Why? Because this child

had a severe disability that required the family to carry her to care for her. They described her functioning to be at the level of an infant. The parents said that they were getting older and were concerned that they would no longer be able to care for their child at home if she got much bigger and had the general issues of growing into womanhood. The court approved the procedure but advocates across the country were troubled by this practice. What is right? I could understand wanting to care for the child at home. But... I also know that our science and ability to help people is increasing every day. This procedure would prevent development of this girl's body, permanently, no matter what. There is not a simple answer. I fear that we often react without a thorough examination of ethical considerations at times.

In other parts of the Country sterilization was (and may still be) far more widespread. Below are two videos. The first discusses sterilization practices from the 1920s to today across the United States. That video focusses on the practice done on women of color. The second video is about sterilization of people with Developmental Disabilities in Europe and current efforts to eliminate the practice. In my opinion, it is long past time to open this conversation again in the U.S.A.

<https://www.youtube.com/watch?v=AhPAs8bOeBg>

<https://www.youtube.com/watch?v=v-siHYAKPwY>

Rights of Recipients



There were at least three large lawsuits against Maine's three large institutions ultimately leading to the closing or significant restructuring of them. Pineland closed its doors on June 1, 1996. There was a key ceremony where every attendee was provided a button and one of the many keys that were used to lock residents into their rooms. The picture above describes key number 709 and the actual key is behind it. During the ceremony attendees literally threw the keys into the local pond. The action was to symbolize that instead of putting people in institutions and locking the doors the keys were going to be thrown away and there would no longer be any locked doors legal in Maine without heavy oversight.

Maine has a document called the “Rights of Recipients” of any MaineCare (Medicaid) service. These rights includes things like no restraint, no locked doors, access to friends and family whenever they want, access to a phone, and access to privacy. If a right needs to be removed, providers and doctors need to justify the action by going through a human rights panel. Maine’s process is called the “three person committee.” Where any plan that would remove a right must be overseen regularly to ensure that the individual is being treated as humanely as absolutely possible.

Assessment

Discussion

<https://www.youtube.com/watch?v=r5GZXp5ewzY>

Review video above and reflect on the positives and negatives of genetic screening in relation to people who live with disabilities? Do you think some of the practice could become Eugenics? What do you think the future of genetic screening should be like?

Assignment (MARK, do you think this should be a special assignment instead?)

<https://shadowsofpineland.org/timeline/#timeline-post-720>

The Shadows of Pineland timeline documents how the service systems have been structured over the last 400 years in Maine. The purpose of this assignment is for you to review the timeline through the lens of various themes so that you can experience the various cycles of policy.

Skills and Knowledge

Gain knowledge of the history of institutions in Maine through the lens of what services were available.

Identify societal issues related to people with Developmental Disabilities in Maine and discuss how we might address these issues today.

Write an academic paper in a word processor.

Upload the paper to the appropriate assignment dropbox

Task

Review the Shadows of Pineland website with a special concentration on the timeline. Throughout the timeline there are a variety of themes identified. Use the timeline to review the instances in history where these themes re-occur and reflect on the below prompts. Then write an essay reflecting on 2 things that you found particularly interesting.

Themes, and the symbols that the website uses to highlight the themes, include:



Money – The financial resources allocated to the service systems that support people with Developmental Disabilities frequently varied. Review the timeline for instances in which resources are discussed and reflect on how the resources met, or didn't meet, the needs of people with disabilities.



Values - Who and what do we value in our society? Review the timeline for evidence that demonstrates what the service systems say about how our society values people with disabilities in light of history.



Institutional Bias - It is easy to assume that institutions are the right place for people with significant needs – in an institution, the assumption is that we can keep them “safe”, provide all the care they need in one place, and people with disabilities can live with “people like them”. Review the timeline and identify how institutional bias worked into the policies and laws until the systems and the biases were intertwined and interchangeable. Reflect on why this bias continues to be so common despite repeated studies documenting the cost ineffectiveness, reduced lifespan, reduced quality of life, and reduced efficiencies of institutionalization.



Waitlists – We hear about people waiting to access services today, but this is not a recent problem. Review the timeline and identify the various times through history when there were waitlists. What do you think contributed, and contributes, to waitlists?



Workforce - We hear about the “workforce crises” in Maine today. But, like waitlists, this is a recurring problem. Despite workforce being vital to people with disabilities, those that are employed in this field often feel undervalued and overworked. Review the times through history that there were challenges with workforce. Reflect on what you think might contribute to this situation. Do you have any ideas how this issue might be fixed?

Criteria for Success

Use the rubric below as a guide to this assignment

Title Page 10 points

Standard title page with name, date, course, college name, and the name of the assignment

Theme: Money 10 points

Review the timeline for instances in which resources are discussed and reflect on how the resources met the needs of people with disabilities.

Theme: Values 10 points

Review the timeline for evidence that demonstrates what the service systems say about how our society values people with disabilities in light of history.

Theme: Institutional Bias 10 Points

Review the timeline and identify how institutional bias worked into the policies and laws until the systems and the biases were intertwined and interchangeable. Reflect on why this bias continues to be so common despite repeated studies documenting the cost ineffectiveness, reduced lifespan, reduced quality of life, and reduced efficiencies of institution.

Theme: Waitlists 10 points

Review the timeline and identify the various times through history when there were waitlists. What do you think contributed to waitlists?

Theme: Workforce 10 points

Review the times through history that there were challenges with workforce. Reflect on what you think might contribute to this situation. Do you have any ideas how this issue might be fixed?

Essay Reflection Something Learned 1 15 points

Topic is clearly labeled, described, and why the student found this interesting is reflected.

Essay Reflection Something Learned 2 15 points

Topic is clearly labeled, described, and why the student found this interesting is reflected.

Mechanics 10 Points

Spelling, syntax, and organizational structure of the paper. Clear and organized