VIDEO TRANSCRIPT

Genetics, History & the American Eugenics Movement

Link to video.

Slide 1


Genetics, History and the American Eugenics Movement

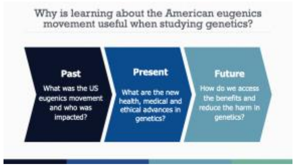
THE GENE

2020

WETA

New genetic technologies are allowing us to assess and alter our own DNA and that of other living things. With this technology comes excitement about the potential for treating disease, as well as fears that some applications could lead to a new era of eugenics. This lesson, in combination with our lesson "Using Primary Sources to Examine the History of Eugenics", will explore the eugenics movement that began in the United States in the early 20th century. The goal is to provide a historical foundation to consider when discussing the benefits and implications of genetic technologies that are emerging today.

Slide 2


Why is learning about the American eugenics movement useful when studying genetics?

Past
What was the US eugenics movement and who was impacted?

Present
What are the new health, medical and ethical advances in genetics?

Future
How do we access the benefits and reduce the harm in genetics?

This lesson is divided into three sections. It begins with an overview of the ways in which genetic technology is currently being used and its implications for health, medicine and ethics. The lesson then traces the history of the American eugenics movement through historical events and documents. Finally, the lesson concludes by highlighting efforts to halt eugenic practices and looks ahead to emerging issues at the intersection of genetics, health, and informed consent.

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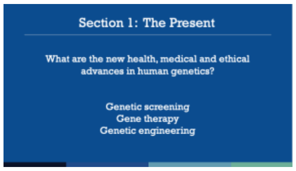
Section 1: The Present

What are the new health, medical and ethical advances in human genetics?

Genetic screening
Gene therapy
Genetic engineering

Section One focuses on the present, highlighting some of the new health, medical and ethical advances in human genetics, including genetic screening, gene therapy, and genome editing. While we will give a quick overview here, these topics are explored in more depth in our "Genome Editing and CRISPR" lesson. We often recommend following this lesson with that one.

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Genetic is used to help make health and medical decisions

A genetic test revealed actor Angelina Jolie carried a mutation in the BRCA1 gene. She chose to undergo a double mastectomy as a result.

Genetic testing can sometimes help guide what medicines are the safest and most effective for an individual to take.

Genetics is increasingly used to make medical decisions - for diagnosis, to identify potential health risks, and to choose medications that are safer and more effective for each patient.

In 2013, Actor Angelina Jolie publicly shared her experience using genetic testing to identify her genetic risk of breast cancer (which ran in her family) and her subsequent choice to have a preemptive double mastectomy.

Genetic tests can also be used to predict how the body may metabolize a drug, and can affect the dosage or whether the medication is prescribed at all.

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Families using genetics to prevent deadly childhood diseases: Moly & Adam Nash

- Illness: Fanconi anemia (disorder of DNA repair)
- Cure: PGD, umbilical cord blood stem cells

Although genetic testing has been used for decades to select certain traits in human embryos, the story of the Nash family brought it into the public eye. Pictured here are siblings Molly and Adam Nash. Molly was born in 1994 with a deadly disorder called Fanconi Anemia (FA), a genetic condition that often leads to cancer.

As a young child, Molly needed a stem cell transplant to save her life. Her parents wanted another baby and decided to use a method of embryo screening with the goal of conceiving a child who would not have FA and would be a perfect donor match for Molly. Using in vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD), Molly's brother, Adam, was conceived. When Adam was born in 2000, stem cells from his umbilical cord were donated to his sister. Since the transplant, Molly has recovered and both children are doing well.

The Nash family was one of the first in the United States to go public with their use of PGD for donor matching. While many people were supportive, the Nashes also faced criticism that Adam was a “designer baby” and suffered unjust risks, conceived only to help his sister.

For more information on genetic technologies related to reproduction, check out PGED’s lesson on Reproductive Genetic Testing.

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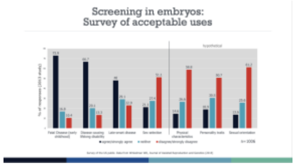

Screening in embryos:
Survey of acceptable uses

People have a range of opinions about the uses and limits of embryo screening, including the use of donor matching (as the Nash family did). In a 2015 study, a majority of the Americans surveyed thought it was acceptable to use PGD to select embryos in order to avoid serious illness or disability, or to identify a match for stem cell donation. Note that close to 20% of people stated it would be acceptable to screen for personality traits and other complex characteristics, even though those options are purely hypothetical. The genetic contributions to complex traits such as personality, intelligence, sexual orientation, and strength are poorly understood, making these characteristics unsuitable to this sort of technology.

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Gene therapy is a potentially powerful tool in treating serious disease

Research is on-going to develop gene therapies for conditions such as sickle cell disease

Beyond reading the genetic code, genetic technology can now be used to alter a person's DNA as treatment for disease – a concept known as gene therapy. One technique that has attracted particular attention is called "genome editing." Clinical trials of genome editing to treat the blood disorder, sickle cell disease (SCD), are currently underway.

Sickle Cell Disease is caused by a change to a single letter in a person's DNA. This change is in the instructions for making hemoglobin, the oxygen-carrying molecule in red blood cells. Typical red blood cells are disk-shaped and easily travel through the blood vessels of the body. The red blood cells of someone with SCD, on the other hand, are crescent or sickle-shaped due to the change in the hemoglobin molecule. Not only does this shape cause them to get stuck in small blood vessels, it also makes them fragile and prone to breaking. Sickle cell disease can be very painful and life-limiting.

Research is currently underway to see if genome editing could be used to help those with sickle cell disease.

One approach involves using genome editing to tell a patient's cells to switch on a gene for an alternate form of hemoglobin that is typically switched off in adults. By switching to this other form of hemoglobin, the red blood cells will no longer sickle.These changes in the blood cells, which would not be passed down to future generations, are showing promise for patients in these early days of clinical trials.

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Genetic engineering reportedly used to alter human embryos, resulting in the birth of twin girls in 2018

The use of genome editing in embryos, such that changes would be passed onto future generations is an area of scientific, legal, religious, and ethical debate. Since 2015, researchers have edited the genomes of embryos, but stated that they had not implanted those embryos into a person's womb. That changed in November 2018 when a scientist claimed that the first two children had been born with genes that had been edited in the embryonic stage. In this case, genome editing was used in an attempt to confer immunity to HIV infection. This case brings attention to many profound ethical issues about potential applications of genome editing in humans.

PGED has an entire lesson devoted to exploring this event and its implications in more detail.

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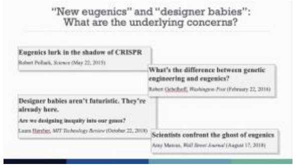

"New eugenics" and "designer babies":
What are the underlying concerns?

Eugenics lurk in the shadow of CRISPR
Robert Pollack, *Science* (May 22, 2015)

What's the difference between genetic engineering and eugenics?
Robert Gebelhoff, *Washington Post* (February 22, 2018)

Designer babies aren't futuristic. They're already here.
Are we designing inequality into our genes?
Laura Hercher, *MIT Technology Review* (October 22, 2018)

Scientists confront the ghost of eugenics
Amy Marcus, *Wall Street Journal* (August 17, 2018)

While many hope that genetic technologies can help to prevent or treat disease, there are many fears as well that the use of genetics (particularly when applied to reproduction) will lead to what is sometimes referred to as "the new eugenics" and "designer babies." These terms are often a short hand to talk about worries that genetics will be used unfairly, to discriminate against groups of people, including people with disabilities. Another major fear is that only the wealthy will have access to the newest advances. A look into our history will show that those concerns are well-founded.

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Section 2: The Past

What was the American eugenics movement and who was impacted?

Eugenic ideology
Legal implementation

Play clip from *The Gene: An Intimate History* (courtesy of WETA)

In Section Two, we will explore the American eugenics movement, including the philosophies and agendas that drove the policies that allowed forced sterilizations, which aimed to prevent certain people passing on what were deemed "negative" traits to future generations.

To begin, please watch this clip from The Gene: An Intimate History.

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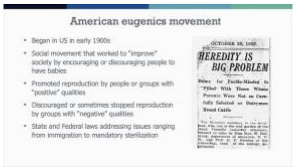

American eugenics movement

- Began in US in early 1900s
- Social movement that worked to "improve" society by encouraging or discouraging people to have babies
- Promoted reproduction by people or groups with "positive" qualities
- Discouraged or sometimes stopped reproduction by groups with "negative" qualities
- State and Federal laws addressing issues ranging from immigration to mandatory sterilization

HEREDITY IS BIG PROBLEM

Home for Feeble-Minded Is Filled With Those Whose Parents Were Not as Carefully Selected as Dairymen Breed Cattle

As we learned in the film, the American eugenics movement began in the early 20th century. The main goal was to improve society and reduce the burden of people who some considered to be inferior. The movement encouraged reproduction among people or groups seen to have "positive" qualities while discouraging or preventing reproduction among those with "negative" qualities.

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A changing American society: Immigration and urbanization

The late 19th and early 20th centuries brought an enormous amount of change to the United States. The nation began to shift from an agrarian to an industrial economy and society, millions of immigrants arrived, and cities grew at an exponential rate. These changes created social challenges, including increased poverty, slums, disease and child labor. Eugenicists believed that immigrants from Southern Europe were genetically inferior, as were people living in poverty (meaning, they were poor because they were genetically predisposed to be lazy). Although incorrect, eugenicists believed that preventing poor people and immigrants from reproducing would solve many societal issues.

One tactic used by eugenicists to limit the population of those deemed 'undesirable' was restriction of immigration.

The US Immigration Restriction Act of 1924 was strongly influenced by eugenicists, who lobbied and worked closely with members of Congress to shape the legislation. The act severely restricted immigration, particularly of Eastern European Jews, Italians (as well as other Southern Europeans), and Africans, and banned the immigration of Arabs and Asians. This act prevented thousands of European Jews attempting to flee persecution by the Nazis from entering the United States during the 1920s and 30s.

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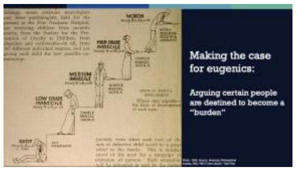

Making the case for eugenics:

Arguing certain people are destined to become a "burden"

Despite many scientists' skepticism and outright rejection, some people began defining different levels of intelligence through the use of specific tests. It was around this time that IQ tests were created. This illustration shows how people were categorized by the mental age that eugenicists believed they would reach and the type of work eugenicists believed they would be able to perform. Part of the goal of eugenicists was to show that "genetically inferior" people would become a burden to society.

Intelligence is a complex trait that is still not well understood. The early IQ tests, and some would argue even modern IQ tests, do not account for environmental, cultural, or social factors that may impact performance. Poor performance on an IQ test in the early 20th century could result in a person being institutionalized or sterilized for "feeblemindedness."

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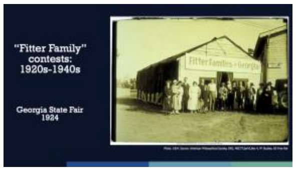
"Fitter Family" contests: 1920s-1940s

Georgia State Fair 1924

Various states and organizations promoted so-called "positive" eugenics by encouraging people who were deemed superior to have more children. The first "Fitter Family" contest, which was based on "Better Babies" contests, was held at the Kansas State Fair in 1920. Both types of contests took a deterministic view of genetics and biology and assumed that there were "good genes" for characteristics such as honesty, morality and industriousness that were passed on to children. The Red Cross originally sponsored these competitions; families were judged in categories including size of family, attractiveness, health and generosity.

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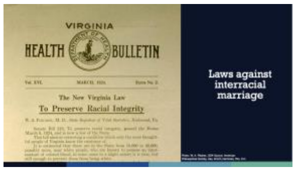
VIRGINIA HEALTH BULLETIN

The New Virginia Law

To Preserve Racial Integrity

Laws against interracial marriage

Many states had laws forbidding interracial marriage from the late 17th century until 1967, when the Supreme Court ruled in Loving v. Virginia that such laws were unconstitutional. Eugenic ideas lent a new set of justifications for such laws by providing a pseudoscientific explanation for the perils of "race-mixing."

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Forced sterilizations were common in Puerto Rico

- Eugenics sterilization law in effect from 1937 to 1960
- "In 1976, the US Department of Health, Education, and Welfare reported that over 37% of women of childbearing age in Puerto Rico had been sterilized. The vast majority were in their twenties."
- Poverty that resulted largely from colonization was used as justification for eugenics

Surgical sterilization, a procedure that prevents a person from reproducing, was a key tool of eugenics programs throughout the United States. Sterilization techniques could include hysterectomy, tubal ligation ("tying tubes") and vasectomy. Forced sterilization programs were underway in many places by 1937, including Puerto Rico and other US territories. Under Law 116, one-third of women in their twenties were sterilized in Puerto Rico according to a report from the United States Department of Health, Education and Welfare. As such, the impact of that law persisted for generations. While overpopulation was cited as the reason for widespread poverty on the island – and therefore a justification for the sterilizations – historians argue that the history of colonization and the sugar industry better explain the poverty on the island. Additionally, Puerto Rico was without full constitutional rights until 1947 and did not have a democratically elected governor until 1948. Law 116 remained in effect in Puerto Rico until 1960.

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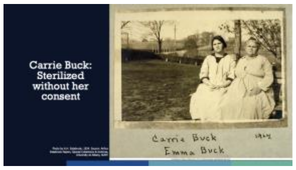

Carrie Buck: Sterilized without her consent

Eugenicists used the US legal system to create a pathway for programs where people could be sterilized without their consent by local and state public health authorities. Carrie Buck was born in 1906 to a poor mother who was eventually committed to the Virginia State Colony for Epileptics and the Feebleminded. Carrie was placed in foster care. At age 17, Carrie became pregnant as the result of being raped, most likely by the nephew of her foster parents. Her foster parents then committed her to the Virginia State Colony on the grounds of feeblemindedness, promiscuity and incorrigible behavior. In 1927, Carrie was the plaintiff in the Supreme Court case Buck v. Bell, which established that the state has the right to force a person to be sterilized without their consent. Carrie was sterilized to prevent passing along "feeblemindedness," which she, her mother and her daughter were all declared to exhibit. (Note that "feeblemindedness" was not well-defined, but a catch-all term applied to those with mental disabilities but also arbitrarily applied as a way to "deal with" women who were not "behaving properly". In the case of Carrie Buck, reporters and researchers who later interviewed her described her to be of average intelligence.)

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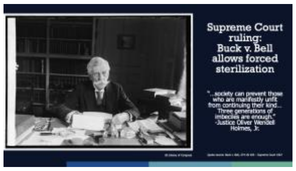

Supreme Court ruling: Buck v. Bell allows forced sterilization

"...society can prevent those who are manifestly unfit from continuing their kind... Three generations of imbeciles are enough." -Justice Oliver Wendell Holmes, Jr.

The case of Buck v. Bell was decided 8-1 by the US Supreme Court. Justice Oliver Wendell Holmes, Jr., writing an opinion for the majority, argued that the interest of the state to improve the gene pool superseded that of the individual's right to maintain bodily integrity. He wrote:

"We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough."

While many cases have criticized the Buck v. Bell ruling, the decision has never been overturned.

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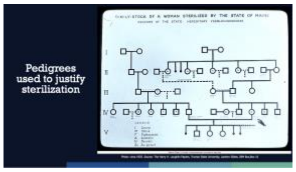

Pedigrees used to justify sterilization

Eugenicists often used pedigrees like the one seen here to trace the pattern of inheritance in a family and justify sterilization. This slide shows a pedigree from a woman sterilized by the state of Maine. Eugenicists "scored" family members and traced the lineage of "defective" as well as "superior" individuals. Pedigrees traced traits such as immoral behavior, degeneracy, criminality, disease, shiftlessness, intelligence and feeblemindedness and gave the impression they were inherited genetically. Environmental factors such as poverty and access to education (which may provide a much more likely explanation for why, for example, criminality or "low intelligence" seems to run in a family) were largely ignored. While there was essentially no sound scientific basis for the genetic inheritance of these types of characteristics, the creation of pedigrees based on these characteristics, nevertheless, helped to establish these ideas as legitimate science.

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American eugenics and German Nazism

"Now that we know the laws of heredity, it is possible to a large extent to prevent unhealthy and severely handicapped beings from coming into the world. I have studied with interest the laws of several American states concerning prevention of reproduction by people whose progeny would, in all probability, be of no value or be injurious to the racial stock."
-Adolf Hitler (1931), quoted in Hitler – Memoirs of a Confidant by Otto Wagener

"Germany is perhaps the most progressive nation in restricting fecundity among the unfit [...] In America it is probable that the sentiment of the people is not ready for the adoption of the German plan, and will be inclined to restrict compulsory sterilization to a small proportion of those who might properly be regarded as especially fit subjects for this treatment. Until public sentiment can be molded to look at the matter in a scientific spirit, it will be necessary to employ moral persuasion in getting the largest possible number of assents to advice for the application of this treatment."
-Editorial in New England Journal of Medicine (1934)

German scientists and eugenicists were greatly influenced by the work of prominent American eugenicists, the two groups exchanging papers and visiting one another's labs and offices. The United States passed its first law allowing sterilization in 1907, 26 years before Germany passed their laws. Here, on the left, we see a quote from Adolf Hitler in which he claims to have learned from American eugenic policies. On the right is an excerpt from the New England Journal of Medicine commending the sterilization program implemented in Nazi Germany.

Many prominent people of the time supported eugenic efforts. The Rockefellers, who were oil and banking magnates, used their family wealth through their foundation to help support the German eugenics program. They funded the program where Josef Mengele worked before he became a physician at Auschwitz, for which he is known as the "Angel of Death". Later, the Rockefeller Foundation would pay to relocate approximately 300 Jewish scholars out of Germany to escape Hitler's regime.

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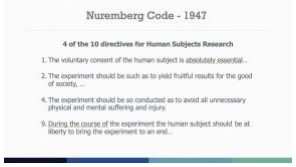

Nuremberg Code - 1947

4 of the 10 directives for Human Subjects Research

1. The voluntary consent of the human subject is absolutely essential...
2. The experiment should be such as to yield fruitful results for the good of society, ...
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end...

The Nuremburg Code was established in 1947 as a result of the "Doctor's Trial," which was intended to bring justice to victims of medical experimentation in Nazi Germany. Among the lengthy list of crimes that were prosecuted in the trial were the Nazi's efforts to develop mass sterilization techniques that could be performed without the victims being aware of it, including secretly exposing them to dangerous x-rays. The Nuremberg Code sought to prevent such atrocities from happening again by establishing protections around voluntary consent and safety in medicine and research. One of the core protections of the Nuremberg Code is the informed consent of willing participants. These codes have guided the development of many medical and research studies with positive outcomes, including successful clinical trials and drug development.

However, the Nuremberg Code was not a cure-all, and did not halt unethical practices related to the American eugenics movement and forced sterilization. By WWII, many scientists in the US had rejected earlier scientific theories that had provided the justification for the eugenics movement, but these ideas had taken root in many state governments and public health initiatives. With the weight of the Buck vs. Bell ruling behind them, sterilizations continued.

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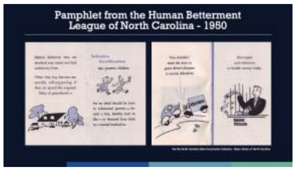

Pamphlet from the Human Betterment League of North Carolina - 1950

This pamphlet, which aimed to persuade the public about the merits of sterilization, was published by an organization called the Human Betterment League of North Carolina. James Hanes (of the Hanes clothing and hosiery company) founded the organization in 1947. The goal of the organization was to promote the sterilization of those deemed mentally unfit. North Carolina had an aggressive state-run push to sterilize people, overwhelmingly women and girls, many of whom were rape victims who were deemed "promiscuous." Others were considered to be intellectually inferior, classified as "morons," "idiots" or "feebleminded." People with mental illness as well as physical illness, such as epilepsy, were also sterilized.

2,990 of the almost 7,600 sterilizations in North Carolina were performed on people between the ages of 10 and 19. The total number of 7,600 includes only those operations directed by the state eugenics board and not those performed locally, and likely unreported, by an individual doctor or hospital.

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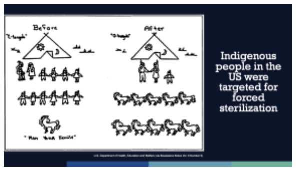

Indigenous people in the US were targeted for forced sterilization

Indigenous people were specifically targeted for sterilization, as part of a longer history of mistreatment and erasure of Indigenous people in the United States. This image, produced by the US Department of Health, Education and Welfare, sought to link sterilization to increased wealth and happiness. The image on the left depicts a larger family with 10 children, parents who are unhappy, and less wealth, represented by the lone horse. Whereas the picture on the right shows a much smaller family, with happy parents, and a lot of wealth. We often ask people to guess when they think this image was produced. They are often surprised to hear it was in 1974!

In 1976, the US Government Accounting Office released its finding that 3,406 sterilizations were performed at Indian Health Service (IHS) centers between 1973-1976. Given the number of stories they and other community members had heard about indigenous women being forcibly sterilized, Dr. Constance Redbird Pinkerton (a Choctaw-Cherokee physician) and Marie Sanchez (a chief tribal judge) each decided to conduct their own research. Through their efforts to document the experiences of many indigenous people, they found significant differences with the number of procedures that were recorded. As a result, some researchers believe that the number of women who were sterilized is much higher than initially reported. Adding to the trauma of these events is the evidence that many of the sterilizations, often done without consent, were conducted at IHS centers that were intended to help and support people living on reservations.

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Section 3: The Future

How do we access the benefits and reduce the harm in genetics?

Efforts to safeguard against future injustices

In many cases, forced sterilizations only came to a halt through the activism and advocacy of the groups of people being targeted. Section Three highlights the work of activists, policymakers and scientists to bring awareness to the stories of those affected by eugenics practices and right the wrongs of the past, ushering in a new era of safeguards against future injustices.

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Protests against forced sterilization began to change minds and policies

Protests against forced sterilization took place around the nation during the 1970s, including the one in North Carolina pictured here. Though many individuals opposed the practice from the start, protests against forced sterilization grew out of the civil rights and women's movements. Many states, including California, outlawed the practice in the mid and late 1970s.

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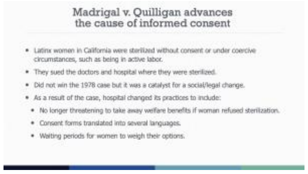

Madrigal v. Quilligan advances the cause of informed consent

- Latinx women in California were sterilized without consent or under coercive circumstances, such as being in active labor.
- They sued the doctors and hospital where they were sterilized.
- Did not win the 1978 case but it was a catalyst for a social/legal change.
- As a result of the case, hospital changed its practices to include:
  - No longer threatening to take away welfare benefits if woman refused sterilization.
  - Consent forms translated into several languages.
  - Waiting periods for women to weigh their options.

In the 1978 Madrigal v. Quilligan case, ten working-class Latinx women who were coerced into sterilization or sterilized without their consent brought a federal class action suit against the doctors who sterilized them and the Los Angeles County Hospital. The case was inspired by women talking with one another and coming forward, and more broadly, by the Chicano Movement that sought rights and fair treatment for Mexican migrants, among others. While the women lost their case, it was key in revising the way in which informed consent was carried out in the medical industry. Until the lawsuit, consent forms were only in English and consent was often sought during active labor and with threats of withholding everything from pain medicine to future welfare benefits. Additionally, rules such as waiting periods for decisions about sterilization after birth were implemented. The documentary "No Más Bebés" shares the stories of the women from this case.

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Secretly sterilized at age 14, Elaine Riddick successfully fought for recognition and compensation in North Carolina

Watch an Associated Press 3-minute long video about Elaine Riddick: [illegible]

Elaine Riddick has been an outspoken survivor of North Carolina's forced sterilization program. She was born into poverty and raised by her grandmother. At the age of 13, she was raped by a man in her neighborhood and became pregnant. She gave birth in March 1968 and was sterilized immediately afterward without her knowledge or consent. Her grandmother, who was illiterate, signed the consent form for sterilization out of fear that Elaine would be sent to an orphanage if she refused. Elaine did not discover what had happened to her until she married and tried to conceive a child. In 2011, the governor of North Carolina established a commission to determine how much to compensate Elaine and the estimated 1,500 to 2,000 other living victims of sterilization. There was much debate about whether any amount of money could compensate for not only the loss of fertility, but also the branding of victims as feebleminded and promiscuous.

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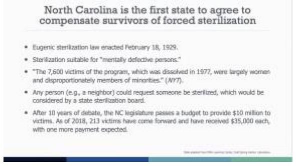

North Carolina is the first state to agree to compensate survivors of forced sterilization

- Eugenic sterilization law enacted February 18, 1929.
- Sterilization suitable for "mentally defective persons."
- "The 7,600 victims of the program, which was dissolved in 1977, were largely women and disproportionately members of minorities." (*NYT*).
- Any person (e.g., a neighbor) could request someone be sterilized, which would be considered by a state sterilization board.
- After 10 years of debate, the NC legislature passes a budget to provide $10 million to victims. As of 2018, 213 victims have come forward and have received $35,000 each, with one more payment expected.

North Carolina became the first state in the United States to approve payments to victims of its eugenic sterilization programs in 2013, after 10 years of debate and legislative votes. The state officially sterilized at least 7,600 people. As of February 2018, reparations of $50,454 have been paid to 220 victims. The only other state to pay compensation is Virginia, agreeing in 2015 to pay victims $25,000 each.

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Echoes of the past:
Sterilization in the 2000s

Judge to inmates: Get sterilized and I'll shave off jail time
Derek Hawkins, *Washington Post* (July 21, 2017)

Following reports of forced sterilization of female prison inmates, California passes ban
Hunter Schwarz, *Washington Post* (September 26, 2014)

Sterilization continues to make headlines, often as it relates to incarcerated people and criminal sentencing. Investigative reporting revealed in 2014 that from 2006-2010 at least 132 inmates in California prisons were sterilized illegally. The sterilizations were characterized by unsigned consent forms, falsified documents, and women stating they were coerced. Much of the sterilization programs were propelled forward through racism and promises of economic relief and stability. One of the doctors involved in a high percentage of the sterilizations noted to a reporter, that the costs of sterilizations were small "compared to what you save in welfare for these unwanted children." New laws were passed as a result to better protect inmates and improve consent procedures.

In 2018, however, a woman awaiting sentencing underwent sterilization, after the judge suggested this could favorably impact how long she was incarcerated. Many argued this was coercive, as the pressures of a possible shorter sentence make true informed consent impossible.

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Oversight on privacy, research and health disparities by the National Institutes of Health

The National Institutes of Health (NIH) oversees the funding and conduct of millions of dollars in medical research, and plays an important role in making sure medical research is fair, safe and equitable. NIH protections for human research continue to adapt to the changing field of genetics. In addition to state-level action, the United States government works to ensure that progress in science, research and technology proceeds in an ethical and socially acceptable manner, so as not to see echoes of the past repeated.

They require coursework, training, and external review bodies to oversee research, offer certifications of confidentiality, and work to ensure that individuals such as women, children and minorities are included in clinical research. At the same time, federal agencies continue to struggle to recruit a fair and representative sample of the population to participate fully in the benefits of scientific advancement.

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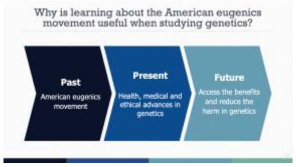

Why is learning about the American eugenics movement useful when studying genetics?

Past
American eugenics movement

Present
Health, medical and ethical advances in genetics

Future
Access the benefits and reduce the harm in genetics

While advances in genetics bring hope for the betterment of human health, they also bring fear of a new eugenics era - where genetic technologies have the potential to be used in ways that are harmful and that increase inequity. By looking at the history of the American eugenics movement, we can learn how genetics has been used as a tool to justify human rights violations, and critically assess how we can move forward without repeating the mistakes from the past.