Genetics, History and the American Eugenics Movement

Adapted for PBS LearningMedia in partnership with WETA for use with:

KEN BURNS PRESENTS THE GENE AN INTIMATE HISTORY 2020
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?
Section 1: The Present

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

- Genetic screening
- Gene therapy
- Genetic engineering
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.
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
Screening in embryos: Survey of acceptable uses

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.
Genetic engineering reportedly used to alter human embryos, resulting in the birth of twin girls in 2018.
“New eugenics” and “designer babies”: What are the underlying concerns?

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

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

What’s the difference between genetic engineering and eugenics?
Robert Gebelhoff, Washington Post (February 22, 2016)

Scientists confront the ghost of eugenics
Amy Marcus, Wall Street Journal (August 17, 2018)
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)
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
A changing American society: Immigration and urbanization

Photo by Lewis Hine (via the Brooklyn Museum)

Photo by Jacob Riis (via the Preus Museum)
Making the case for eugenics:

Arguing certain people are destined to become a “burden”
“Fitter Family” contests:
1920s-1940s

Georgia State Fair
1924
The New Virginia Law
To Preserve Racial Integrity


Senate Bill 219, To preserve racial integrity, passed the House March 8, 1924, and is now a law of the State.

This bill aims at correcting a condition which only the more thoughtful people of Virginia know the existence of.

It is estimated that there are in the State from 10,000 to 20,000, possibly more, near white people, who are known to possess an intermixture of colored blood, in some cases to a slight extent it is true, but still enough to prevent them from being white.
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

Carrie Buck: Sterilized without her consent

Photo by A.H. Estabrook, 1924. Source: Arthur Estabrook Papers, Special Collections & Archives, University at Albany, SUNY.
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.

Quote source: Buck v. Bell, 274 US 200 – Supreme Court 1927
Pedigrees used to justify sterilization

Photo: circa 1935. Source: The Harry H. Laughlin Papers, Truman State University, Lantern Slides, IBM Box, Box 10
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)
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...
Mental defectives who are sterilized may marry and lead satisfactory lives.

Often they may become reasonably self-supporting if they are spared the responsibility of parenthood.

Selective Sterilization
also protects children

for no child should be born to subnormal parents — denied a fair, healthy start in life — or doomed from birth to a mental institution.

You wouldn’t want the state to grant driver’s licenses to mental defectives

Nor expect such defectives to handle money wisely.
Indigenous people in the US were targeted for forced sterilization.
Section 3: The Future

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

Efforts to safeguard against future injustices
Protests against forced sterilization began to change minds and policies

Southern Conference Educational Fund (SCEF)
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.
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: https://www.youtube.com/watch?v=I WANJoxW2s4&t=10s

Photo permission via Adam David Kissick, https://www.adamkissick.com
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.

Slide adapted from DNA Learning Center, Cold Spring Harbor Laboratory
Echoes of the past: Sterilization in the 2000s

Judge to inmates: Get sterilized and I’ll shave off jail time

Following reports of forced sterilization of female prison inmates, California passes ban
Hunter Schwarz, *Washington Post* (September 26, 2014)
Oversight on privacy, research and health disparities by the National Institutes of Health

Coverage and Reimbursement of Genetic Tests
Payers such as insurance companies and Medicare need systematic ways of evaluating genetic tests for reimbursement.

Genetic Discrimination
In 2008, the Genetic Information Nondiscrimination Act was passed into law, prohibiting discrimination by employers and health insurers.

What is Genome Editing?
Genome editing is a method that lets scientists change the DNA of many organisms, including plants, bacteria, and animals.

Health Disparities
NHGRI wants to ensure that all populations benefit from the advances of genomics research.

Human Subjects Research
Federally-funded research with human participants must comply with regulations that protect the rights and welfare of the participants.

Informed Consent
Informed consent shows respect for personal autonomy and is an important ethical requirement in research.

Courtesy: National Human Genome Research Institute (https://www.genome.gov/issues/)
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Prescription bottle image courtesy of Dana Bateman

Slide 5: Photo by Mark Engebretson, University of Minnesota.


Image credits


  https://www.law.berkeley.edu/php-programs/centers/crrj/zotero/loadfile.php?entity_key=QFDB5MW3

Slide 25: The Southern Conference Educational Fund (SCEF), Louisville, Ky. Via U.S. National Library of Medicine


References


