# Introduction to Genetics, Ethics, & Society

**GENE 220** 





### Acknowledgement Statement

We would like to begin by acknowledging that we meet today on the ancestral and unceded land of the Muwekma Ohlone Tribe. This land was and continues to be of great importance to the Ohlone people. As an uninvited guest on these lands, We are a beneficiary of the ongoing displacement of the Ohlone people. We pay our respects to the Native peoples, past and present.

We would like to acknowledge the suffering and resilience of all people whose lives and livelihoods were stolen by those with power, including but not limited to the millions of enslaved African American people. The devastating effects of these injustices continue to be felt today.

We would like to acknowledge everyone who has a lived experience of oppression, be it racism or sexism, classism or ableism, transphobia or homophobia, or any other form of oppression. To ignore oppression is to assent to oppression.

We appreciate and respect the knowledge and personal experience of everyone gathered here and we thank you for choosing to share your time and energy to be here today.

### Your TAs!











### Personal Introductions

Share your name and pronouns

#### Session Outline

- Introduction to the course
- Introduction survey
- Who's in the room activity
- Creating ground norms
- History lecture
- Diversity activity
- Introduction to positionality
- Journal activity
- Wrap up

Introduction to the course (!!)

### Learning goals for the quarter

- Connect the historical context of genetics research to its modern-day practice
- 2. Evaluate the social and ethical implications of genetics research
- Analyze how societal norms and structures, along with personal identities, biases, and responsibility, impact the conduct of scientific research

#### Course Outline

Week 1: Introduction to the course, history of genetics

Week 2: Introduction to bioethics, social responsibility, and community engagement

Week 3: Race, ancestry, identity, and genetics Part I

Week 4: Race, ancestry, identity, and genetics Part II

Week 5: Genetic determinism and social responsibility revisited

Week 6: Sex and gender; ability

Week 7: Screening and selection

Week 8: Identification and privacy

Week 9: Library Archives Visit

Week 10: Self-reflection and action

### Syllabus

- Expectations for us & expectations for you
- Content considerations
  - Please prioritize your well-being with regards to emotionally difficult content
- Grading/attendance
- Accommodations & other resources
- Anonymous feedback: bit.ly/GENE220-feedback

### Grading

- Must attend 8/10 sessions to pass
- Please reach out to Roshni or Rachel if you have any concerns, we will be accommodating of any unforeseen circumstances



#### Covid19 Ground Rules

- We highly recommend to remained masked throughout the lectures and discussions
- If you have covid, or any reason to believe you might have covid, please stay home! We will provide you a virtual way to see the class.



### Optional research survey (15 min)

This survey will be available for 24 hours to complete (note: this is easier to take on a laptop)

## Session 1: Introduction to History of Genetics

### Session 1: Introduction to the history of genetics

#### Learning goals

- Co-create ground norms for discussions throughout the course by sharing personal identities and experiences.
- Understand how societal biases intersected with genetic research and medicine through the 20th century.



Taught by Alanna Pyke (she/her)



Taught by Justin Gomez-Stafford (he/they)

### Who's In The Room?

5 minutes

### What words would you use to describe yourself?





### Community Norm Building

### Ground norm building

- We will co-create ground norms together. Take a moment to consider spaces where you have felt comfortable and empowered to engage.
  - What about those spaces stands out to you?
- Reflect on the identities you have seen others share.
  - What norms would you like to have to feel safe/respected moving forward?
- You are invited to make suggestions of how we will build a respectful space during this course.

### Agreed Upon Group Norms

- Be respectful of conflicting opinions
- Commit to learning and growing
- Compassionate listening
- No talking over anyone
- Make space, take space

#### **Ground Norms From Class**

- Be respectful of conflicting opinions
- Commit to learning and growing
- Compassionate listening
- No talking over anyone
- Make space, take space
- What is said in the room, stays in the room (confidentiality)
- Use "I"statements for sensitive topics
- Don't equate people with stereotypes
- Don't rush to judge others

### History of Genetics

### The origins of heredity

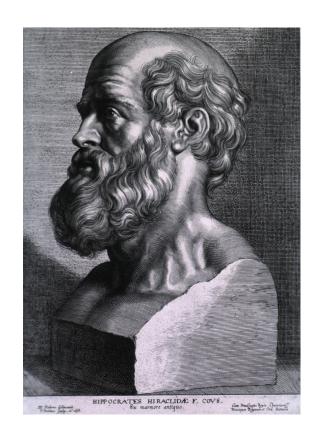
- A legal term indicating the rules and rights of an heir and of succession.
- Many Roman legal cases were concerned with heredity and property inheritance.
- Families became invested in tracking heredity.



Ahnentafel von Herzog Ludwig (1568-1593)

### How did heredity relate to physical traits?

- Greek and Roman thought
  - Hippocrates (460 370 BCE)
    - Both parents produced "semen" or seminal fluids that intermingled to create the embryo
    - Mixed traits were explained by the blending of male and female seminal fluids
  - Aristotle (384 322 BCE)
    - Germs in female menstrual blood were formed into a new living being by the movement of the paternal seed
    - Environmental attributes in the womb (temperature, age, diet, etc...) affected the gender of the newborn



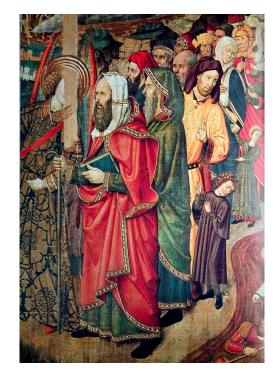
#### "Good" and "bad" blood

- In Medieval Europe, "blood" became the defining factor that related kinship between families.
- Nobles would pass their "good" blood onto their offspring and people with "bad" blood would do the same.
- Even animals had blood statuses. Falcons especially were renowned and could not be mated with lower birds at risk of tainting their good blood.



## The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

- The term "race" came about to describe groups of individuals who shared the same nationality, ethnicity, and/or religion
- Early examples in the 1400s in Spain:
  - Non-christians, especially Jews were often persecuted and denied social status and land ownership.
  - Sentencia-Estatuto barred Jewish converts to Christianity who couldn't prove four generations of affiliation from holding private or public office and receiving church land grants
- Race becomes linked to heredity as a justification for slavery



"Retaule de Sant Bernardí i l'Àngel Custodi" -Jaume Huguet

## The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

- Before the 16th century, slavery was largely linked to religion (specifically non-Christian faiths)
- Over time, we see the legalization of a new hierarchy based on race
  - Race becomes linked to heredity as a justification for slavery



## The historical linking of heredity and race is inextricably tied to Christian hegemony and colonialism

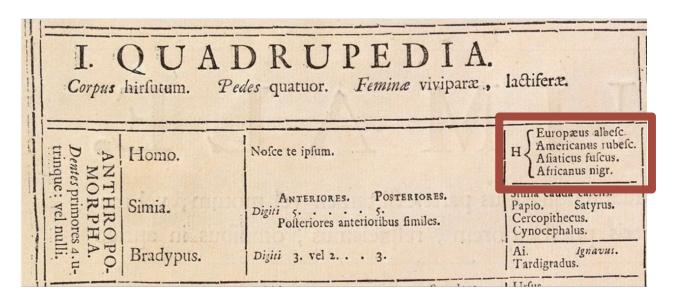
- 1662 Virginia enacted a law of hereditary slavery (maternal)
- 1667 Virginia rules enslaved people stay enslaved even if they convert to Christianity

The justification for black servitude changes from a religious status to a designation based on race



# "Scientific" understanding of heredity was influenced by society and reinforced racial hierarchies

1737: Carl Linnaeus' Systema Naturae



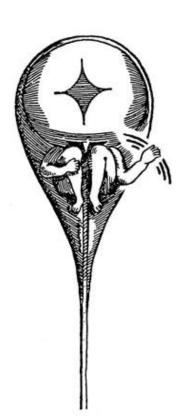
## Theories about the mechanisms for heredity changed between the 17th and 19th centuries

#### Preformation

 Humans were pre-formed and simply unfolded from either the egg or the sperm (spermist vs ovist)

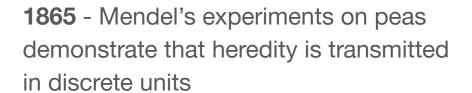
#### Epigenesis

Human form gradually emerges and is influenced by the environment

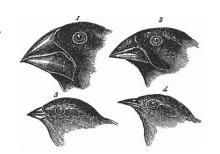


## Theories about the mechanisms for heredity changed between the 17th and 19th centuries

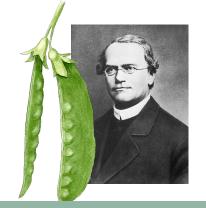
**1859** - Darwin publishes *On The Origin of Species*, describing a theory of natural selection



**1911** - Morgan's work with fruit flies shows that genes are carried on chromosomes





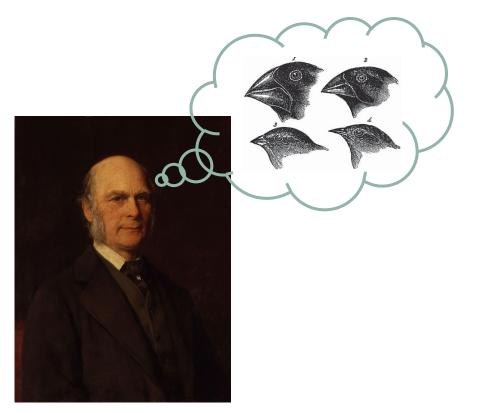


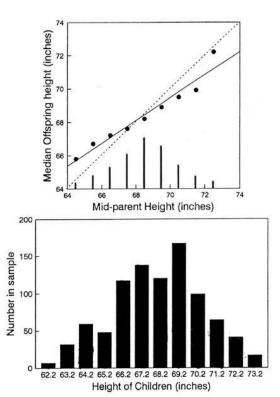
Changed the viewpoint on heredity largely from environmental to deterministic



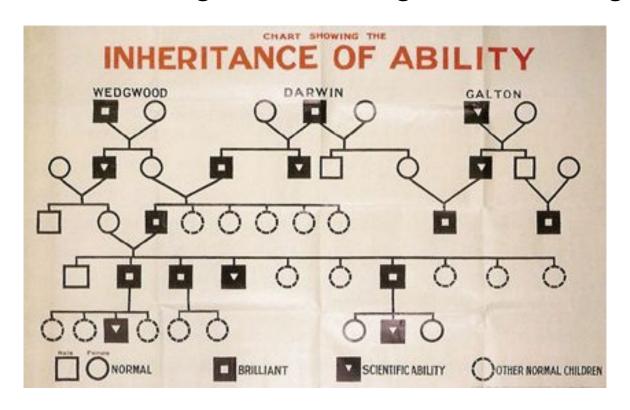
### American eugenics

## Inspired by Darwin, Francis Galton becomes interested in whether human traits are heritable





Galton becomes particularly interested in studying human differences and intelligence, coining the term "eugenics"



### American eugenics movement

- Began in US in early 1900s
- Social movement that worked to "improve" society by encouraging or discouraging people to have babies
- Filled with progressives

OCTOBER 29, 1926.

### HEREDITY IS BIG PROBLEM

Home for Feeble-Minded Is

Filled With Those Whose
Parents Were Not as Carefully Selected as Dairymen

Breed Cattle

The Women's Auxiliary to the dairymen, who met in the roof garden of the Hotel Vermont yesterday afternoon, listened to talks by Miss Sara M. Holbrook, department of education, U. V. M., and Prof. H. F. Perkins of the University, head of the zoology department.

Eugenics promoted reproduction by groups with positive

qualities



Eugenics discouraged reproduction by groups with negative qualities

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 bo to subnormal parents—d nied a fair, healthy start life—or doomed from bir to a mental institution. Photo: W. A. Plecker, 1924 Source: American Philosophical Society, Dav. B:D27..Harriman, Mrs. E.H.

## VIRGINIA

HEALTH BULLETIN

Vol. XVI.

MARCH, 1924.

Extra No. 2.

### The New Virginia Law To Preserve Racial Integrity

W. A. PLECKER, M. D., State Registrar of Vital Statistics, Richmond, Va.

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 thought-

ful 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.

wisely.

es



Via the North Carolina State Documents Collection. State Library of North Carolina

The rise of the birth control movement was tied to eugenics

"birth control is nothing more or less than the facilitation of the process of weeding out the unfit [and] of preventing the birth of defectives"

"[eugenicists] imply or insist that a woman's first duty is to the state; we contend that her duty to herself is her duty to the state"



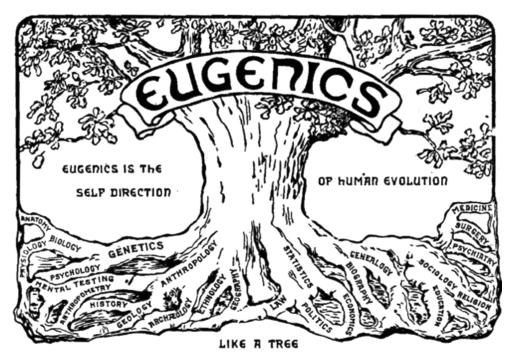
Margaret Sanger

# Eugenics was especially popular in the midst of a changing American society

- 1. Immigration
- 2. Urbanization
- 3. Settler-colonialism



# Moreover, eugenics was repeatedly legitimized by scientists and mathematicians

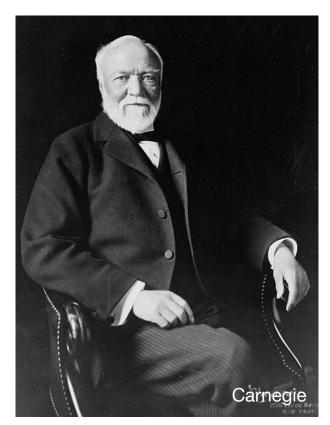


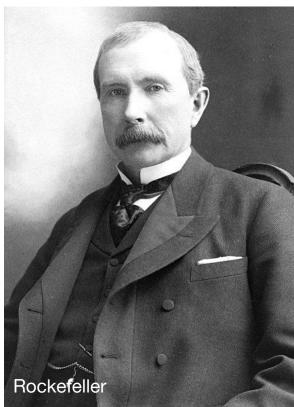
GUCGNICS DRAWS ITS MATERIALS FROM MANY SOURCES AND ORGANIZES
THEM INTO AN HARMONIOUS ENTITY.

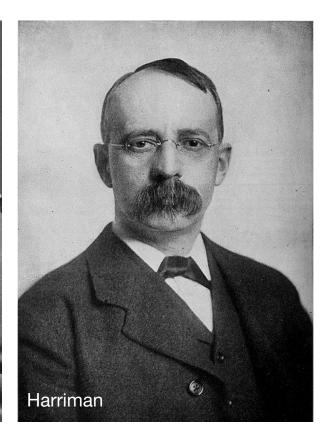
# Moreover, eugenics was repeatedly legitimized by scientists and mathematicians



### Capitalism enabled the spread of eugenics







### California legalizes forced sterilization in 1909

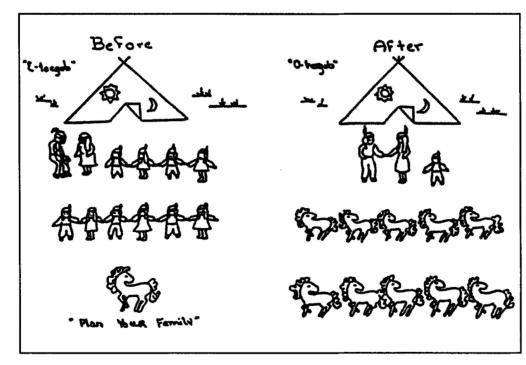
- Allowed superintendents at state psychiatric institutions to sterilize patients to improve their "physical, mental, or moral condition."
- Mental deficiency broadly defined
  - sexual promiscuity, schizophrenia, alcoholics, epileptics, individuals with Down's syndrome, depressed, criminal, feebleminded (by IQ)



Agnews Developmental Center, Santa Clara, California

# Black, Latina, and Indigenous women were especially targeted for forced sterilization

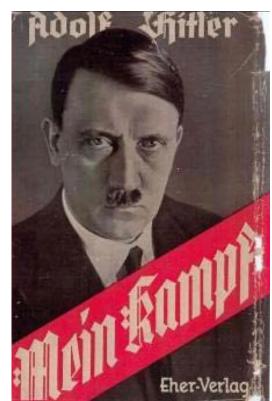
- Latina women were 59%
   more likely to be sterilized
   than non-Latina women
- African Americans made up 1% of California's population but 4% of the sterilizations
- 20,000 sterilizations over4 decades



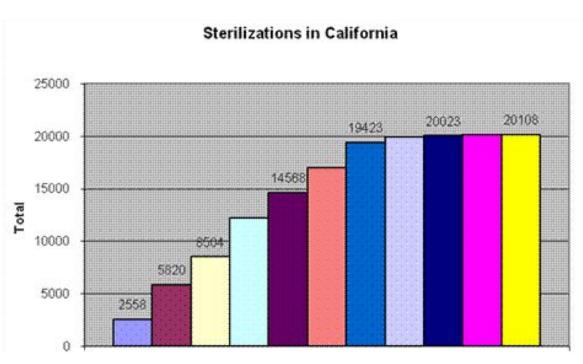
American eugenics was a big source of inspiration for Germany

"I have studied with great interest the laws of several American states concerning prevention of reproduction by people whose progeny would... be of no value or be injurious to the racial stock."

"There is today one state in which at least weak beginnings toward a better conception (of immigration) are noticeable. Of course, it is not our model German Republic, but the United States."



### Eugenics decreases in popularity following the Holocaust

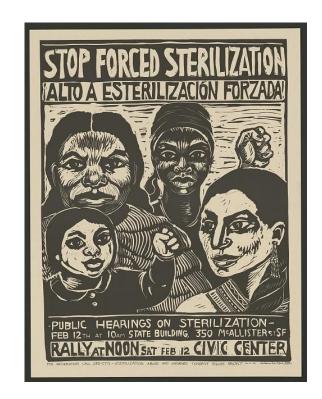


https://www.uvm.edu/~lkaelber/eugenics/CA/CA.html

#### Sterilizations continue into the late 20th century

#### Madrigal v. Quilligan (1978)

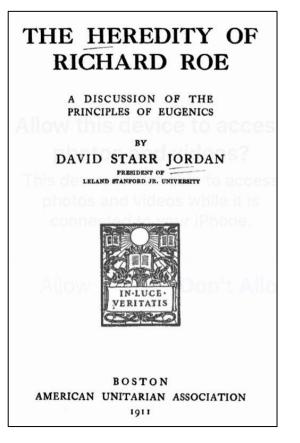
- Civil rights class action lawsuit filed by 10
   Mexican American women against the LA
   County-USC Medical Center for involuntary
   or forced sterilization
- Judge ruled in favor of the county
- Ruling influenced the California Department of Health to implement new sterilization procedures, including bilingual informational materials that explained the process and consequences of sterilization



# Eugenics at Stanford

#### Eugenics at Stanford – David Starr Jordan

- First president and Chancellor of Stanford
- promoted sterilization
- Led the first explicitly eugenic organization in the United States, as chairman
- Co-founded the Human Betterment
   Foundation (HBF) which promoted the expansion of sterilization programs, publishing pamphlets to be used by lawmakers and schools.



https://www.stanfordeugenics.com/

### Eugenics at Stanford - David Starr Jordan

- Large advocate on sterilization
  - "limitation by public authority of the marriage of the defective, the insane, and the criminal."
- regularly gave talks on the "Negro Problem."
  - Solution: mixing of white and black races to improve black people through the introduction of white blood
- Anti-immigration
  - "The dangers of foreign immigration lie in the overflow to our shores of hereditary unfitness."



### The Outdoors and Eugenics – Redwoods

More important, the redwoods symbolized the commonality of the threat to both nature and the Nordic elite: the uncontrolled, rapacious forces of industrial expansion. While the Nordics were being threatened by the high birth and immigration rates of inferior foreigners seeking work, the redwoods were being threatened by humans themselves – the

Without intervention and conservation – indeed preservation – both redwood and Nordic would pass into extinction and be lost forever.

The preservation of the redwoods, of the bison, of the Alaskan caribou, of the bald eagle... of the spirit of the early American colonist,... and of the purity of the 'Nordic' type of humanity in this country, were all his personal concerns, all products of the same urge in him to save precious things. (June 2, 1937)



### Eugenics at Stanford – Lewis Terman

- Education professor
- Wanted to identify eugenically gifted children to allocate the most resources to.
- Developed the Stanford-Binet IQ test to measure the ability of children
- Modern IQ tests are based off of this



#### Eugenics at Stanford – Ellwood Cubberly

- Dean of Education
- Worked with Terman to find the most eugenically gifted children and allocating the most resources to their education.
- feared the eugenic impact of immigration

"their coming has served to dilute our national stock and to weaken and corrupt our

political life."



### Eugenics at Stanford – Thomas Storey

- Eugenics was taught to Stanford the first few decades of the 1900s as part of mandatory courses on hygiene and health.
- Taught theories of eugenics and racial health
- taught that "the relation of pauperism, mental degeneracy and crime to heredity justifies community interference"



Storey House is an undergraduate resident theme house for Human Biology

#### Eugenics at Stanford - Ray Lyman Wilbur

- third president of Stanford University, serving between 1933 and 1943
- supported an expansion of eugenic education for college students.
- Expanded Stanford's medical and hygiene programs, which were often used to teach Stanford students the science of eugenics.





#### Eugenics at Stanford – Edward Ross

- Professor of Economics
- Credited with popularizing the theory of race suicide:
  - low birth rates and increased immigration would lead to the extinction of the white race.
- Particularly concerned with Asian immigration, fearing the destruction of the "Anglo-Saxon character of American society"
- Because of his anti-Asian rhetoric and his criticism of the railroad industry, Jane Stanford successfully called for his resignation



### Eugenics at Stanford – Luther Burbank

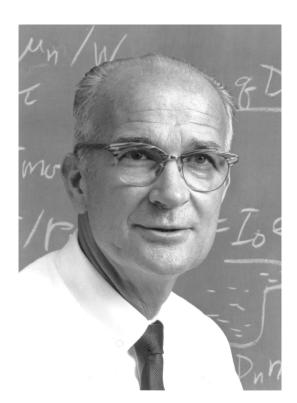
- Plant breeding expert
- Just as the bad qualities of plants can be bred out through crossbreeding, so too could "unfit" qualities in humans be eradicated through eugenics.
  - "it would, if possible, be best absolutely to prohibit in every State in the Union the marriage of the physically, mentally and morally unfit."





### Eugenics at Stanford – William Shockley

- Engineering professor who invented the transistor for which he won the Nobel prize
- Tried to prove the intellectual superiority of white people, using IQ data to "prove" the existence of an intellectual deficiency among black people.
- Re-popularized eugenic-esque thinking in the 1980s and 1990s

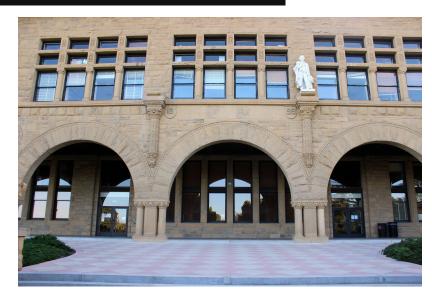


#### Eugenics at Stanford – David Starr Jordan

Stanford President David Starr Jordan's Name To Be Removed From Campus Spaces Over Role In Eugenics Movement



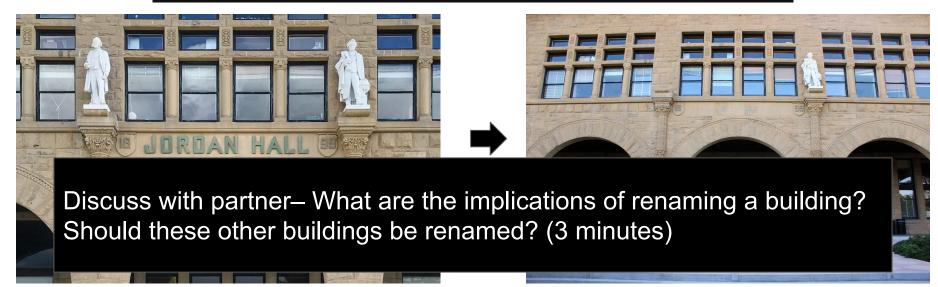




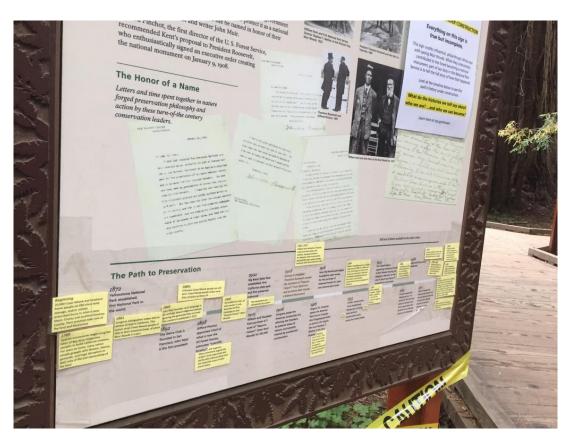
https://www.stanfordeugenics.com/

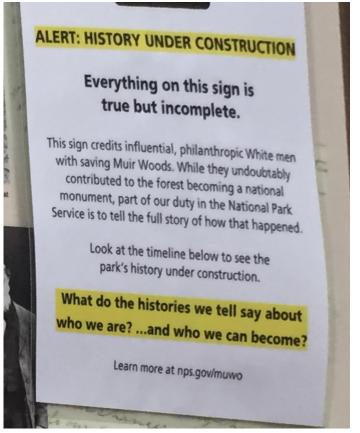
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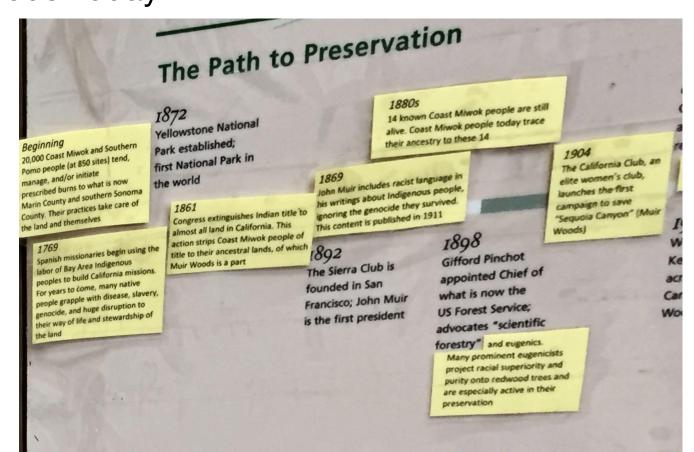


### Muir Woods Today





## Muir Woods Today

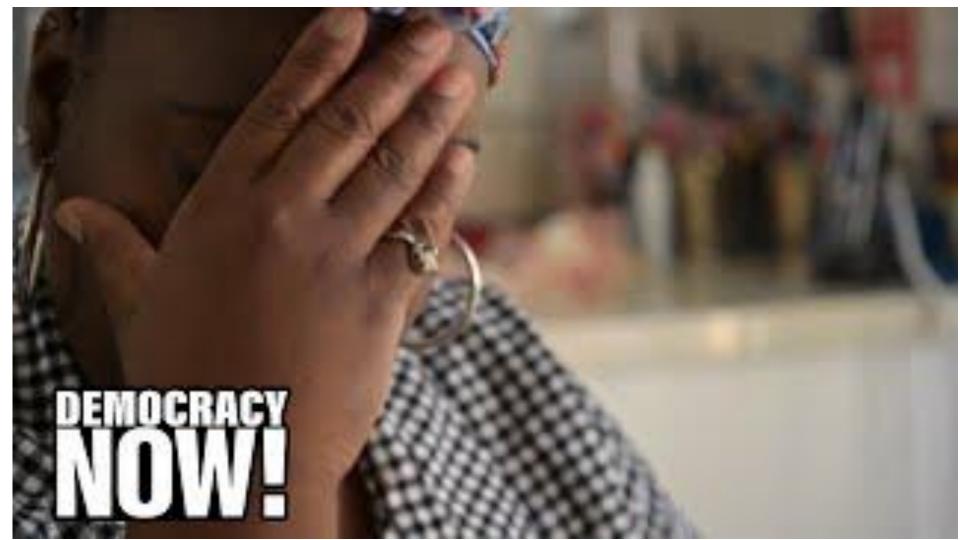


# Eugenics Today

#### Forced Sterilizations in California Prisons until 2014

- Kelli Dillon
  - Told needed surgery to treat an ovarian cyst,
  - unknowingly underwent a hysterectomy in 2001
  - Informed of sterilization by lawyer
- California prison sterilizations
  - At least 148 pregnant women received tubal ligations shortly after giving birth
  - Majority were Black and Latina
  - Nearly 1,400 sterilizations between 1997 and 2013
- California banned coerced sterilizations as means of birth control in prisons in 2014, driven in part by Dillon's testimony.





#### Reparations











# California Launches Program to Compensate Survivors of State-Sponsored Sterilization

Published: Dec 31, 2021

New law creates Forced or Involuntary Sterilization Compensation Program

# California tries to find 600 victims of forced sterilization for reparations

State plans to pay \$15,000 to those sterilized against their will in 1930s eugenics movement and more recently in state prisons

#### Discussion (10 min)

What were the different societal and scientific influences that shaped the study of eugenics?

## **Eugenics in Contemporary Politics**



You have good genes. You know that, right? You have good genes. A lot of it is about the genes, isn't it, don't you believe? The <u>racehorse theory</u>. You think we're so different? <u>You have good genes</u> in Minnesota"

- Donald Trump, Minnesota, 9/18/20

"I'm a gene believer... Hey, when you connect two race horses, you usually end up with a fast horse." - Donald Trump

#### US forced sterilization at the US-Mexico Border

- 2020
- Nurses were alarmed by the "rate at which the hysterectomies have occurred"
- "everybody he sees has a hysterectomy"
- One detainee likened the centre to "an experimental concentration camp", adding: "It was like they're experimenting with our bodies."

Immigration Detention and Coerced Sterilization: History Tragically Repeats Itself



Quotes from BBC

## Eugenics and the Internet



"You know with pre-implantation genetic testing we can breed out non-white ancestry fairly easily"

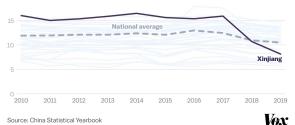
Figure 1: Subreddits with genetic testing related comments, grouped into categories based on their thematic topics.

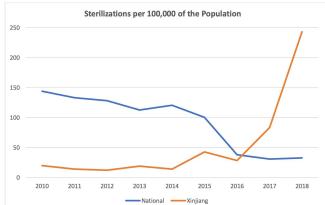
# Current ethnic cleansing against minority populations in China with work camps and forced sterilization



#### Births in China's Xinjiang region have dropped sharply in recent years

Births per 1,000 people in each of China's regions





Diversity of Experiences Activity

### Diversity of Experiences Activity (7 minutes)

Examples of unearned privileges in graduate education will be read to the class.

- If the statement resonates with you Add 1 point
- If the statement does NOT resonate with you Add 0 points

Keep track of your total score.

Pay attention to your reactions to the statements and where you can see these elements come up during your work and life.

# Diversity of Experiences Activity Word Cloud and Reflection

4 minutes

#### Diversity of Experiences Activity Reflection

#### Reflection questions

- Have any of these statements come across your mind?
- How did seeing other people's scores compared to yours affect you?
- How does this change your outlook on your peers, faculty, and/or community?

#### Respond at pollev.com/alannapyke235

Text ALANNAPYKE235 to 22333 once to join, then A, B, C, D, or E

### What range was your total score in?

0-3

4-7

8-11

12-15

16-20

#### ⊕ Respond at pollev.com/alannapyke235

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## What range was your total score in?

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12-15

16-20





Introduction to positionality

#### Positionality, Intersectionality, and Privilege

#### Positionality

- how our individual identities are constructed by cultural and political contexts
- how these identities shape the way we see the world in relation to others

#### Intersectionality

 the complex, cumulative way in which the effects of multiple forms of discrimination combine, overlap, or intersect especially in the experiences of marginalized groups

#### - Privilege

 an advantage that only one person or group of people has, usually because of their position or socioeconomic status



### Sharing of identities in pairs

- Please share some identities with a partner, here's some ideas:
  - Name, pronouns, gender identity, sexuality, ethnicity/race, disability, family role, education level, department, etc.
- Partner up and share ~3mins

Questions to consider:

What do you have in common with your partner?

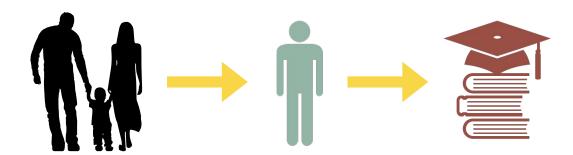
What is different about you and your partner?

What made you decide to take this class and what impact did your identities have on that decision?

#### Journal Activity - Initial Positionality Reflection (10mins)

#### Consider:

- What places are you and your ancestors from?
- How has that shaped your identity?
- How does this impact your positionality?
- How would you say your identities inform how you interact with others around you?



# Session 2: Bioethics, Social Responsibility, and Community Engaged Research

#### Learning goals

- Describe the four principles of bioethics and apply them to case studies
- Identify shortcomings of the four principle of bioethics
- Identify key stakeholders and conflicts of stakeholdership in community-engaged research
- Understand the benefits of social responsibility and community-engaged

research

Taught by Alanna Pyke (she/her)

Taught by Naiomi Hunter (she/her)

#### Readings before next session:

- "Should we make a fuss? A case for social responsibility in science"
- Science under the Scope comic (Sophie Wang)
  - What part of this reading surprised you?
  - What part of this reading made you uncomfortable?
  - What resonated with you?
  - Where have you seen examples of society influencing science in your field of study?



Taught by Alanna Pyke (she/her)



Taught by Naiomi Hunter (she/her)