

Eyes on the Prize:
Some Lessons About Genetic
Anti-Discrimination Efforts Below the 49th Parallel

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On America

“Americans are so enamored of equality that they would rather be equal in slavery than unequal in freedom.”

-- Alexis de Tocqueville

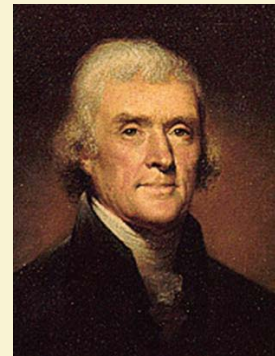


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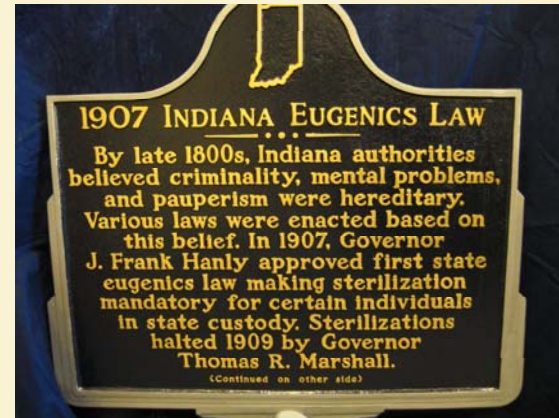
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American Obsessions: Myth or Reality?

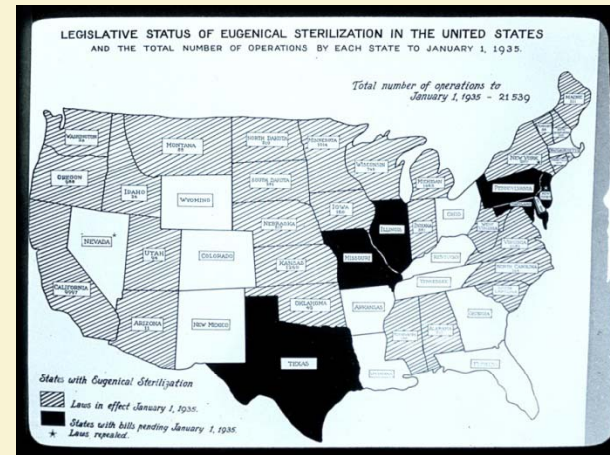
- Primacy of individual rights
- Scope of liberty-limiting principles
- Virtue of reward for labor
- State's rights vs Federal power



“Scientific” Discrimination: Eugenic Sterilization

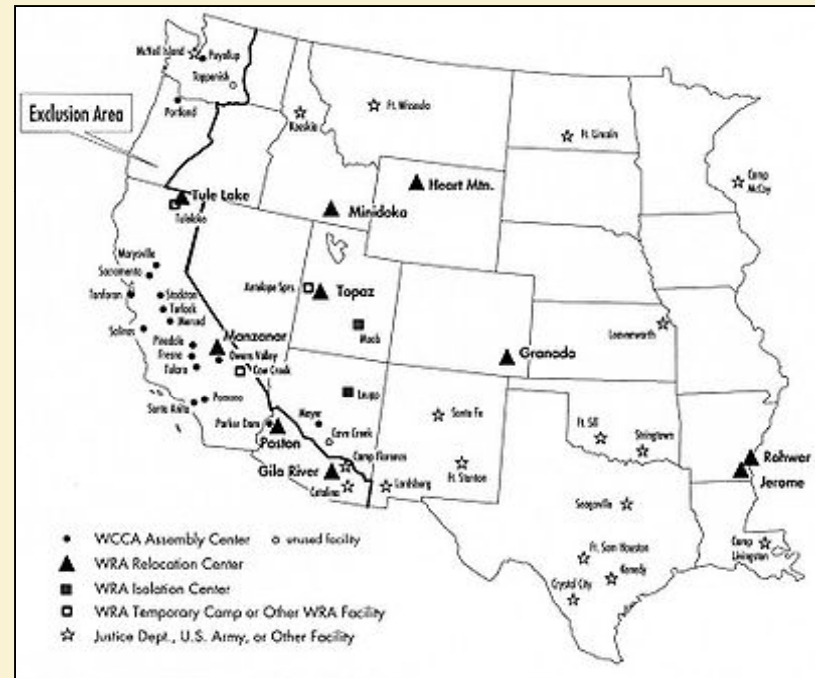


“It is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough.” (Buck v. Bell, 1927)



Racial Discrimination: Japanese Internment “War Relocation” Camps

1942: Roosevelt signs E.O. 9066 authorizing military areas as “exclusion zones”

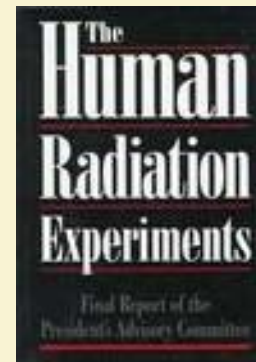


The Power of Apologies for Harm

1988: Reagan's apology to Japanese Americans

1990s: State governors apologizing for eugenic laws

1993: Clinton's apology for radiation experiments, and Tuskegee



“To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry.”

-- Bill Clinton, May 17, 1996

What About Canada?

Canada....

- Permitted eugenic sterilization
- Permitted Japanese internment
- Permitted slavery
- Apologized for treatment of First Nations peoples in residential schools



NOTICE TO ALL JAPANESE PERSONS AND PERSONS OF JAPANESE RACIAL ORIGIN

TAKE NOTICE that under Orders Nos. 21, 22, 23 and 24 of the British Columbia Security Commission, the following areas were made prohibited areas to all persons of the Japanese race:—

LILU ISLAND (including Steveston)	SAPPERTON
SEA ISLAND	BURQUITLAM
EBURNE	PORT MOODY
MARPOLE	IOCO
DISTRICT OF QUEENSBOROUGH	PORT COQUITLAM
CITY OF NEW WESTMINSTER	MAILLARDVILLE
	FRASER MILLS

AND FURTHER TAKE NOTICE that any person of the Japanese race found within any of the said prohibited areas without a written permit from the British Columbia Security Commission or the Royal Canadian Mounted Police shall be liable to the penalties P.C. 1665.

C. TAYLOR,
Chairman,
Security Commission

LAWRENCE HILL

Black Berry, Sweet Juice

On being black and white in Canada
by the author of the national bestseller *Any Known Blood*

A grid of 12 small portraits of people's faces, arranged in three rows of four. The faces show a variety of skin tones and features, illustrating the concept of 'black and white' in the context of the text.

On Discrimination

“In the end antiblack, antifemale,
and all forms of discrimination
are equivalent to the same thing
– antihumanism”

- Shirley Chisholm



“There is hardly a political question in the United States which does not sooner or later turn into a judicial one.”

- Alexis de Tocqueville

“Today's Constitution is a realistic document of freedom only because of several corrective amendments. Those amendments speak to a sense of decency and fairness that I and other Blacks cherish.”

- Justice Thurgood Marshall



Reproductive Discrimination

Griswold v. Connecticut, 381 U.S.
479(1965)



Roe v. Wade, 410 U.S. 113 (1973)



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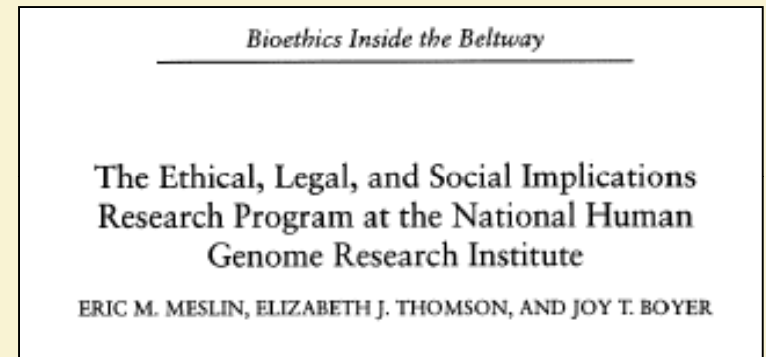
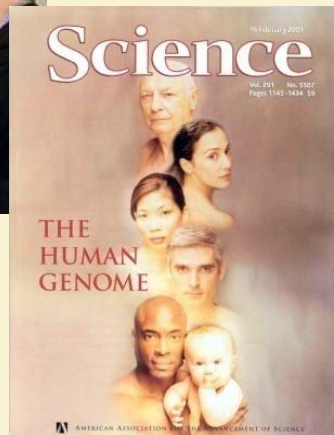
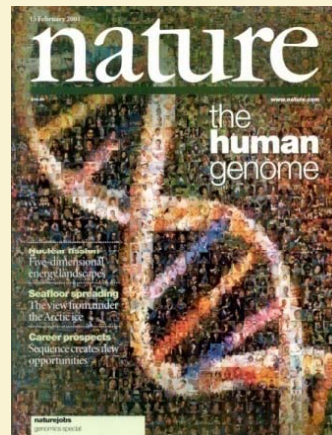
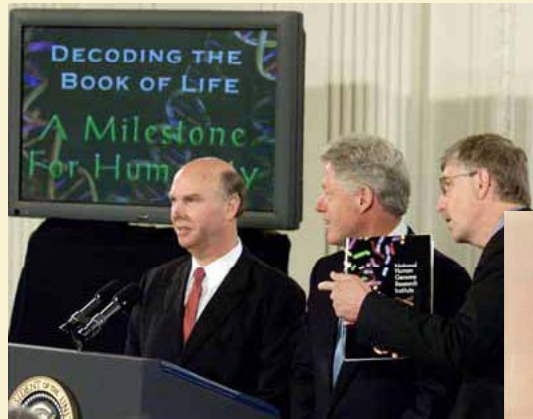
On Privacy

“The right to be let alone is indeed the beginning of all freedom.”

- Justice William O. Douglas, U.S. Supreme Court



The Accelerant Effect of the Genome Project



- ❖ Privacy
- ❖ Genetic Discrimination
- ❖ Stigmatization
- ❖ Informed Consent
- ❖ Patenting
- ❖ Commercialization



George Annas's Model "Genetic Privacy Act" (1995)

"The major goal of the Human Genome Project is to decipher this code so that the information it contains is accessible. The privacy question is, accessible to whom?"

"[B]ased on the premise that genetic information is different from other types of personal information in ways that require special protection."



Biobanks Research: NBAC's Interpretation of the Regs

Recommendation 1:

Federal regulations governing human subjects research (45 CFR 46) that apply to research involving human biological materials should be interpreted by the Office for Protection from Research Risks (OPRR), other federal agencies that are signatories to the Common Rule, IRBs, investigators, and others, in the following specific ways:

- a) Research conducted with unidentified samples is not human subjects research and is not regulated by the Common Rule.
- b) Research conducted with unlinked samples is research on human subjects and is regulated by the Common Rule, but is eligible for exemption from IRB review pursuant to 46.101(b)(4).
- c) Research conducted with coded or linked samples is research on human subjects and is regulated by the Common Rule. It is eligible for exemption unless the specimen or samples are publicly available as defined in 45 CFR 46.101 (b)(4). Few collections of human biological materials are publicly available although many are available to researchers at reasonable cost. OPRR should make clear in its guidance that in most cases this exemption does not apply to research using human biological materials.



- Current research regulations work, but need refining and careful interpretation
- Ethically, coded samples should be considered as equivalent to identifiable samples
- Concern: harm to individuals from unintended disclosure of phenotypic information to unauthorized 3rd parties

US Federal Action on Genetic Discrimination: A Brief Recent History 1995-2000*

1995:

- The Genetic Privacy and Nondiscrimination Act, S. 1416, introduced by Sen. Mark Hatfield and H.R. 2690, introduced by Rep. Clifford Stearns

1996:

- The Genetic Fairness Act, S. 1600, introduced by Sen. Dianne Feinstein
- The Genetic Confidentiality and Nondiscrimination Act, S. 1898, introduced by Sen. Pete Domenici
- **Health Insurance Portability and Accountability Act** enacted

1997:

- January 7: Rep. Clifford Stearns introduces H.R. 341, the Genetic Privacy and Nondiscrimination Act
- January 7: Rep. Gerald Solomon introduce H.R. 328, Genetic Information Health Insurance Discrimination Act

- January 7: Rep. Louise Slaughter introduces H.R. 306, the Genetic Information Nondiscrimination in Health Insurance Act
- January 21: Sen. Olympia Snowe introduces S. 89, the Genetic Information Nondiscrimination in Health Insurance Act
- March 11: Sen. Pete Domenici introduces S. 422, the Genetic Confidentiality and Nondiscrimination Act
- July 17: Rep. Clifford Stearns introduces H.R. 2198, the Genetic Privacy and Nondiscrimination Act
- July 22: Rep. Joseph Kennedy introduces H.R. 2216, the Genetic Protection in Insurance Coverage Act

*Source: Genetics and Public Policy Center



A Brief Recent History cont'd

1999:

- March 4: Sen. Olympia Snowe introduced S. 543, the Genetic Information Nondiscrimination in Health Insurance Act of 1999
- July 1: Rep. Louise Slaughter introduced H.R. 2457, the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999

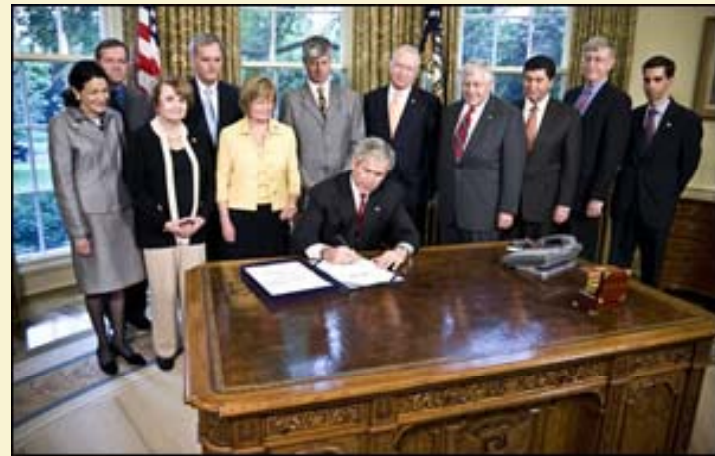
2000:

- February, President Clinton signs **Executive Order 13145**, prohibiting federal agencies from obtaining genetic information about their employees or job applicants and from using genetic information in hiring and promotion decisions.



A Brief History of H.R. 493 aka, the Genetic Information and Nondiscrimination Act (GINA)

- 2001-02: first introduced in the 107th Congress
 - 2003-2004: reintroduced in the 108th Congress; passed the Senate 95-0. House did not consider the bill.
 - 2005-06: reintroduced in the 109th Congress; passed the Senate 98-0. House did not consider the bill.
 - 2007-08: reintroduced in Democratically-controlled 110th Congress; April 25, 2007, passed the House 420-3; April 24, 2008, after being the subject of a “hold” by Sen. Tom Coburn, GINA passed the Senate 95-0.
 - May 1, 2008: sent back to the House of Representatives and passed 414-1 on May 1, 2008 (the lone dissenter was Rep. Ron Paul).
- **GINA signed by GW Bush, May 21, 2008**
 - Prohibits discrimination in health coverage and employment based on genetic information.
 - The statute defines ‘genetic information’, ‘genetic test’



President George W. Bush signs H.R. 493, the Genetic Information Nondiscrimination Act of 2008, Wednesday, May 21, 2008, in the Oval Office. White House photo by Eric Draper.



The Prize

- Improved human health and well being
- A well supported and productive science community
- An environment that encourages technology innovation and translation
- Assured protection against unfair discrimination
- A genetically literate society
- Trustworthy and transparent governance structures



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*“Paul and Silas bound in jail, had no money for to go their bail
Keep your eyes on the prize, hold on, hold on
Hold on, hold on, keep your eyes on the prize, hold on, hold on*

*The very moment I thought I was lost, the dungeon shook and the chains fell off
Keep your eyes on the prize, hold on, hold on
Hold on, hold on, keep your eyes on the prize, hold on, hold*

*Only thing that we did wrong, was stayin’ in the wilderness too long
Keep your eyes on the prize, hold on, hold on
Hold on, hold, keep your eyes on the prize, hold on, hold on*

*The only thing that we did right, was the day we begun to fight
Keep your eyes on the prize, hold on, hold on
Hold on, Hold on, keep your eyes on the prize, hold on, hold on
Hold on, hold on, keep your eyes on the prize, hold on*

-- “Keep Your Eyes on the Prize”, American Civil Rights Folk Song , Lyrics by Alice Wine, Sung by Pete Seeger

Acknowledgements

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