

Making Disability in Prenatal Genetic Testing

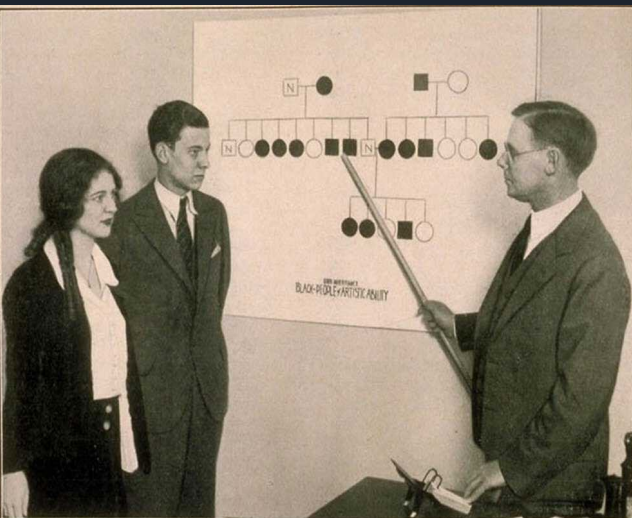
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The 'Shadow' of Eugenics



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Genetic counseling
using pedigree chart

Late 1800s, early 1900s: Biostatisticians use genetics claims to promote eugenic reforms as 'population control.'

1940s: Research centers & clinics develop "genetic hygiene" techniques to address "bad bloodlines."

1956-1966: Identification of genetic conditions, testing innovations.

Throughout: Systematic forced sterilization targeting women of color and low-income white women.

Expectations for Individualized Responsibility

Health management is individual's responsibility (toward the state).

Economic productivity as bodily independence vs. **disability, dependence.**

Public health agenda: screening and abortion of fetuses with genetic conditions as "**cost-effectiveness,**" reducing "**burdens.**"

Reproducing disabled children or parenting while disabled considered "**irresponsible**" or "**irrational.**"

Adjudicating
Existence
in Wrongful Birth
and Wrongful Life
Cases



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Research Methods

How does increasing use of prenatal genetic technologies illuminate changing perspectives about ‘meaningful’ existence?

Who should be responsible for reproducing children along these lines?

- “Casetext” database: **WBL cases related to prenatal genetic testing.**
- Included all WBL cases at **federal appellate courts** and all **California courts.**
- Analyzed cases between **1963** (first case) **and 2021: 37 cases** (16 in California).

Wrongful Birth and Wrongful Life (WBL)

Wrongful Life (WL): brought by or on behalf of the **child** with the genetic condition, alleging their birth was the result of the defendant's negligent prenatal care.

‘Negligence’ deprived parents of “the decision to abort or never conceive.”

Wrongful Birth (WB): brought by **parents** against the healthcare provider for the deprivation of reproductive choice.

Had parents been informed ‘on time’ they would have exercised right to abortion.

Prenatal Genetic Testing Timeline

1950s-1970s

Development and clinical implementation of amniocentesis, an invasive prenatal genetic diagnostic test to sample fetal chromosomes

1973

Roe v. Wade establishes pregnant person's right to abort a fetus

1979

National Institutes of Health release Consensus Statement stating that amniocentesis be routinely offered to women older than 35 years of age

1983

- MSAFP testing developed, enabling prenatal genetic testing via maternal blood draw
- CVS testing developed, allowing invasive diagnostic testing of fetal chromosomes
- ACOG and AAP advise medical practitioners to offer prenatal diagnosis to 'high-risk' pregnant patients

1986

California Prenatal Screening Program established, offering state-wide access to prenatal genetic testing at no cost to patients

2011

Non-invasive Prenatal Testing (NIPT) released into the consumer health market

2007

ACOG states that all pregnant patients, regardless of age, be offered prenatal genetic testing (particularly for Down's Syndrome)

2019

CAPS companies lobby Congress for NIPT coverage

Main Points

- 1) Courts frame disability as **inherently unwanted**; prenatal genetic testing should prevent these outcomes.
- 2) Courts see disability as individually embodied, not socially produced. Disability is a **private burden** for parents and providers to resolve.
- 3) As testing becomes common, courts transform disabilities into **legally cognizable injuries** that warrant damages/compensation.

#1 Technological Expectations

As tech advances, testing for normative health/ability emphasized

Becker v. Schwartz (1978): plaintiff-mother successful in malpractice suit, *but* WL claims dismissed.

Gildiner v. Thomas Jefferson Hospital (1978): “failure to properly perform or interpret an **amniocentesis** could cause [...] the **unwanted birth** of a child afflicted with Tay Sachs disease.”

Curlender v. Bio-Science Lab (1980): Supports systematic de-selection of fetuses with ‘unbearable conditions.’ Defendants’ duty breach is “proximate cause of an **injury cognizable at law.**”

#2 Parental Obligation

Responsibility shifts given prenatal care, but remains individualized

Park v. Nissen (1975): Parental responsibility emphasized.

Curlender v. Biosciences (1980): Physicians accountable for birth of disabled child when testing is standardized.

Berman v. Allan (1979): “In failing to inform Mrs. Berman of the availability of amniocentesis, defendants directly deprived her (and her husband) [...] of the option to accept or reject a parental relationship with the child and **thus caused them to experience mental and emotional anguish upon their realization that they had given birth to a child afflicted with Down Syndrome.**”

#3 Disabilities and Qualifying Life

Courts qualify 'normal vs. non-normal' life & award damages

Gletiman v. Cosgrove (1967): “If Jeffrey could have been asked as to whether his life should be snuffed out [...], our felt intuition of human nature tells us **he would almost surely choose life with defects as against no life at all.**”

Curlender v. Biosciences (1980): what matters is if “a plaintiff exists and suffers, due to the negligence of others,” rather than whether they should have existed at all.

Turpin v. Sortini (1982): “impaired life is not always more valuable than nonexistence.”

Significance

1. Overturning Roe v. Wade emphasizes **family and disability support as private burden**. Diminishes reproductive and disability protections.
2. Prenatal genetic technologies **tied to social and historical legacies**. Can we transform present use, so ableism is not the status quo?
3. Genomic technologies becoming more routine in pregnancy healthcare. Need thoughtful clinical practices and focus on **inclusive social structures**.

References

1. Telling Genes: The Story of Genetic Counseling in America, by Alexandra Minna Stern
2. War Against the Weak: Eugenics and America's Campaign to Create a Master Race, by Edwin Black
3. Enforcing Normalcy: Disability, Deafness, and the Body, by Lennard Davis
4. Precision Medicine and Its Imprecise History, by Christopher Phillips
5. Undoing the Demons: Neoliberalism's Stealth Revolution, by Wendy Brown
6. The Zero Trimester: Pre-Pregnancy Care and the Politics of Reproductive Risk, by Miranda Waggoner
7. Governed through Choice: Autonomy, Technology, and the Politics of Reproduction, by Jennifer Denbow
8. Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?, by Dorothy Roberts
9. Mobilizing Mutations: Human Genetics in the Age of Patient Advocacy, by Daniel Navon
10. Noninvasive Prenatal Genetic Testing: Current And Emerging Ethical, Legal, And Social Issues, by Mollie Minear et. al
11. Testing women, testing the fetus, by Rayna Rapp