

Genetics and Justice:

The Science, Politics and Policy of the New Genetic and Reproductive Technologies



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Center for Genetics and Society



Mission statement: “working to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies”

CGS programs

- *Biotechnology Accountability Program*
- *Gender, Justice, and Human Genetics*
- *Reframing the Debate*

Why we are here...



Emerging genetic and reproductive technologies have the potential to:

- Decrease women's control over their reproduction
- Lead to a “techno-eugenic” future
- Deepen social inequalities



Eugenic Dreams



Eugenics



- “Improving human genetic qualities”
- Convergence of science, technology, and ideology: to selectively “breed” the human population
- Historically pro-science and pro-modernity

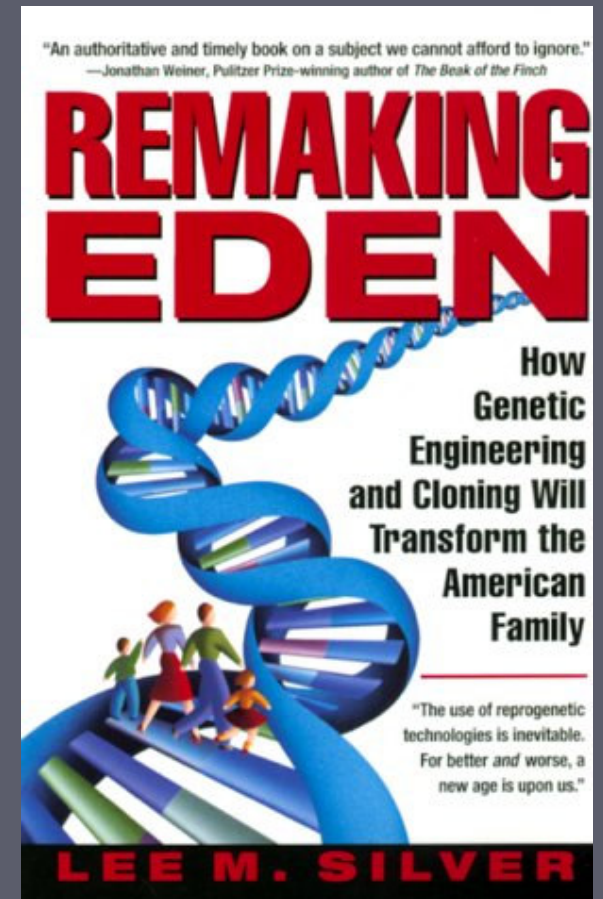


Past	Present	Future
<p>Sterilization</p> <p>Genocide</p> <p>Segregation</p> <p>Restrictive immigration</p> <p>Forced abortion</p> <p>Infanticide</p> <p>Dangerous contraceptives</p>	<p>Sex selection</p> <p>Embryo screening</p> <p>Selective abortion</p> <p>Gamete donor selection</p> <p>Dangerous contraceptives</p> <p>Restrictive immigration</p> <p>“Family” eugenics</p>	<p>Increase pre-implantation diagnosis & screening</p> <p>Reproductive cloning</p> <p>Inheritable genetic modification</p> <p>“Designer babies”</p> <p>Immigration</p>

Professor Lee Silver,
Princeton University



“...the economy, the media, the entertainment industry, and the knowledge industry [will be] controlled by members of the GenRich class....Naturals [will] work as low-paid service providers or as laborers.... [Eventually] the GenRich class and the Natural class will become... entirely separate species with no ability to cross-breed, and with as much romantic interest in each other as a current human would have for a chimpanzee.”



The New Eugenics

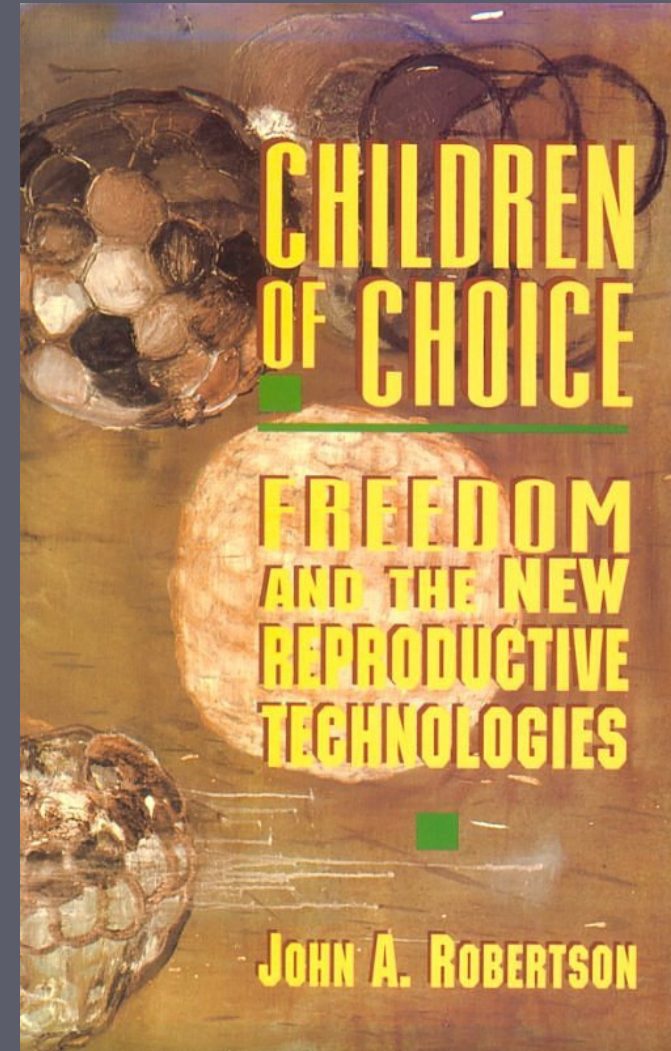


From Chance to Choice

GENETICS &
JUSTICE



ALLEN BUCHANAN, DAN W. BROCK,
NORMAN DANIELS, & DANIEL WIKLER



Prof. Richard Lynn



“The new medical technology of eugenics is going to take off, because it satisfies the needs of individuals... Parents would like to have children who are free of genetic diseases, and potentially in the future they will want to have children who are intelligent... As the technology comes on line to allow them to do this, people will take it up.”

Eugenics: A Reassessment, 2001

Privatized Market Eugenics



- Market-driven race to select or “enhance” genes
- Parents could feel compelled to select child’s characteristics
- Criteria for “good” traits to select would reflect particular social biases



The Science of Selection



Sex selection by sperm sorting



- MicroSort ® -- sorts sperm cells carrying Y-chromosome (male) from X-chromosome (female)
- Costs about \$3,200 per try (most need 3 tries)
- ~ 450 MicroSort babies born
- Ads in *NY Times* and in-flight magazines

The MicroSort® Gender-Selection Program at GIVF

Do You Want To Choose the Gender Of Your Next Baby?



If you want to choose — or need to choose — whether your next baby is a girl or a boy, you may qualify for the MicroSort® gender selection procedure at the Genetics & IVF Institute (GIVF).

Prospective parents come from all over the world to GIVF in suburban Washington, DC. They choose this exclusive *scientifically-based* sperm sorting gender selection procedure, currently in an FDA clinical trial, for several important reasons:

- For prevention of genetic diseases
- For family balancing
- Results so far show 90% success rate for achieving girls and 75% for boys.
- FREE MicroSort for qualifying patients who use Donor Egg or Preimplantation Genetic Diagnosis at GIVF.
- For sensitive, personal attention from a caring staff of professionals, dedicated to the success of your family.

Couples also choose the Genetics & IVF Institute because we are the world's largest integrated provider of infertility and genetic services. Our expertise in the diagnosis and treatment of complex genetic and reproductive disorders is second to none.

To learn more about the Genetics & IVF Institute, and how the MicroSort® technology may help you select the gender of your next child — please visit us at:

www.givf.com
or call us at
1-800-277-6607

Now available in New York and other metropolitan areas through collaborating physicians. Call for details.

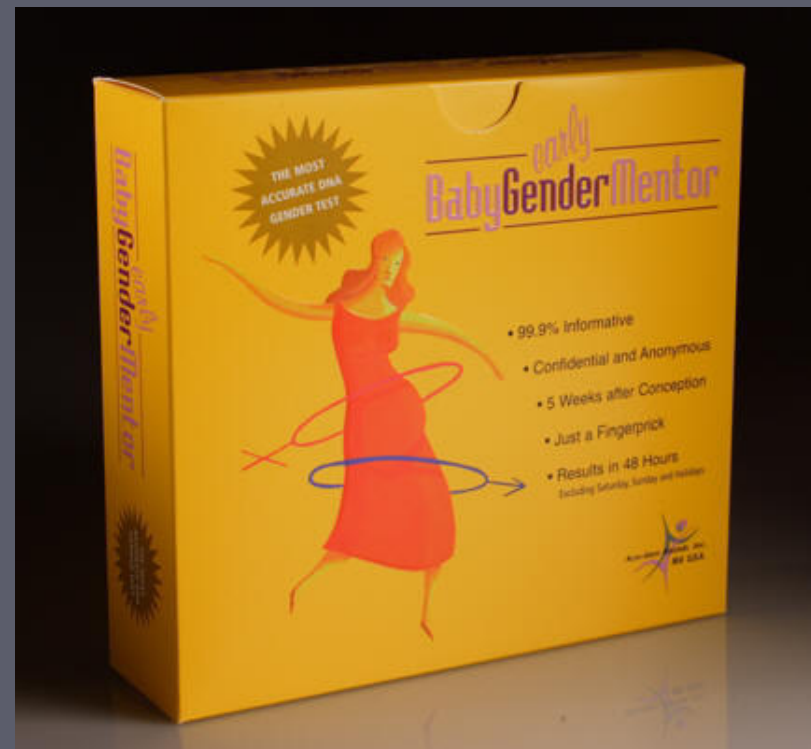
Caution: This procedure uses an investigational device limited by federal law to investigational use.

GENETICS & IVF INSTITUTE 

“At Home” Sex Determination Kits: The Baby Gender Mentor



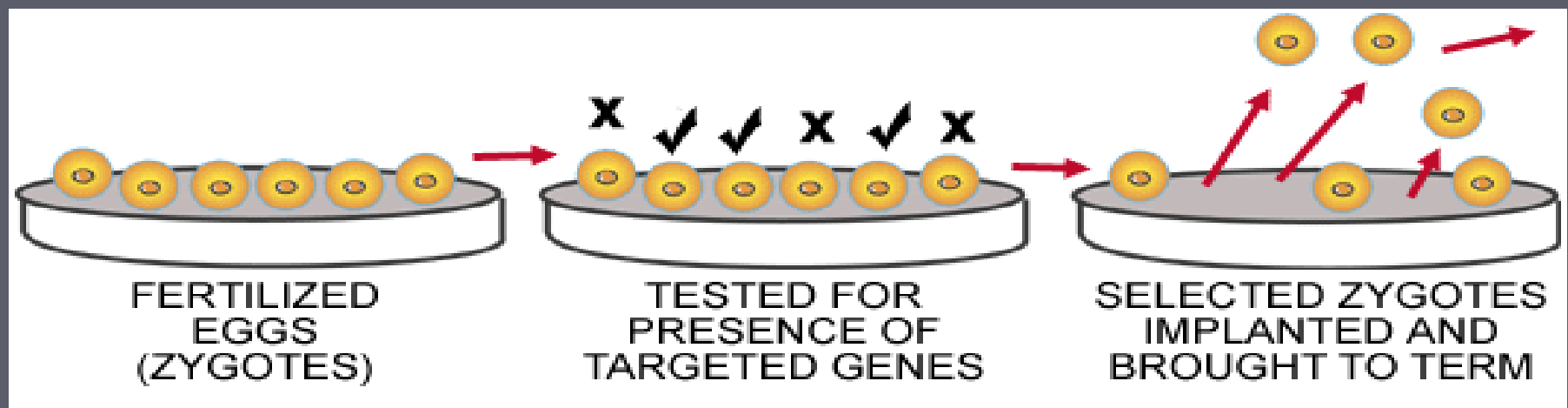
- Tests maternal blood at 5 weeks to determine fetal sex
- Claims 99.9% accuracy
- Costs: \$275 for kit and DNA analysis
- Results given via internet 1-2 days later



Pre-implantation genetic diagnosis (PGD)



- Using In Vitro fertilization, eggs are fertilized
- At day 3 (8 cells) a cell is extracted for testing
- Only selected embryos implanted
- No genes or embryos are modified



Pre-Implantation Genetic Diagnosis (PGD)



- Introduced in 1990s to allow at-risk parents to avoid passing on severe genetic diseases
- More recently, uses have expanded to include
 - sex selection
 - screening for over 100 genetic conditions, from dwarfism and early onset Alzheimer's to Tay Sachs
 - tissue match for existing child needing transplant
- Regulated in most countries; unrestricted in the U.S.
- Costs about \$15,000 per attempt

Disability Rights



- Will people with disabilities be viewed as “mistakes” who should not have been allowed to be born?
- Legacy of abuse of people with disabilities in the name of eugenics



Policy Models and Options



Current Policy in the U.S.



Assisted reproduction—little or no regulation or oversight

- IVF (including use of drugs for egg retrieval)
- PGD
- Sex selection

Models of Effective Regulation



- Canada: Assisted Human Reproduction Act 2004
- UK: Human Fertilization and Embryology Authority (HFEA)

Models of Effective Regulation: Canada



- **Assisted Human Reproduction Act 2004**
 - Regulates assisted reproduction and embryo research in public and private sectors
 - Strongly supported by women's health groups; opposed by anti-abortion groups.
 - Bans IGM, reproductive *and* research cloning, creation of embryos for research, social sex selection, commercial surrogacy, sale of gametes and embryos
 - Allows research on embryos and embryonic stem cells

Models of Effective Regulation: U.K.



- **Human Fertilization and Embryology Authority**
 - Regulates assisted reproduction and embryo research in public and private sectors
 - Members are appointed; at least half must be neither doctors nor scientists involved in human embryo research or providing infertility treatment
 - Licenses and inspects researchers and commercial firms

The Law & Politics of Choice



- These technologies require liberal and progressive minds to think critically about traditional notions of choice
- Allowing traditional notions of choice to enable eugenic applications of these technologies may undermine reproductive rights and social justice
- Right to reproductive privacy/right to choose may not necessarily include right to design