

Powerful Reproductive and Genetic Technologies in an Unjust World:



Envisioning a Path to Justice

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National Consultation on New Reproductive Technologies
and their Implications for Women,

Jawaharlal Nehru University, New Delhi, India

January 5, 2007

Center for Genetics & Society



- “working to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies”
- Gender, Justice and Human Genetics
 - Reproductive Health and Human Rights
 - Race, Disability and Eugenics
 - Race, Health and Environmental Justice
- Biotechnology in the Public Interest
 - Stem Cells in California
 - Stem Cells Nationally

Our Work



Social justice organizations & leaders

- Outreach and education
 - Build their capacity and understanding to integrate & engage
 - Cross-movement relationships, engagement & dialog
 - Multi-movement coalition-building
-
- Reframe the Stem Cell Debate
 - Media & communications
 - Policy recommendations

Outline of Talk



- Context
- Ask the key POLITICAL questions
- Make the connections and build the relationships – technologies, issues & movements
- Strategies
- Lessons from our work

Emerging technologies are:



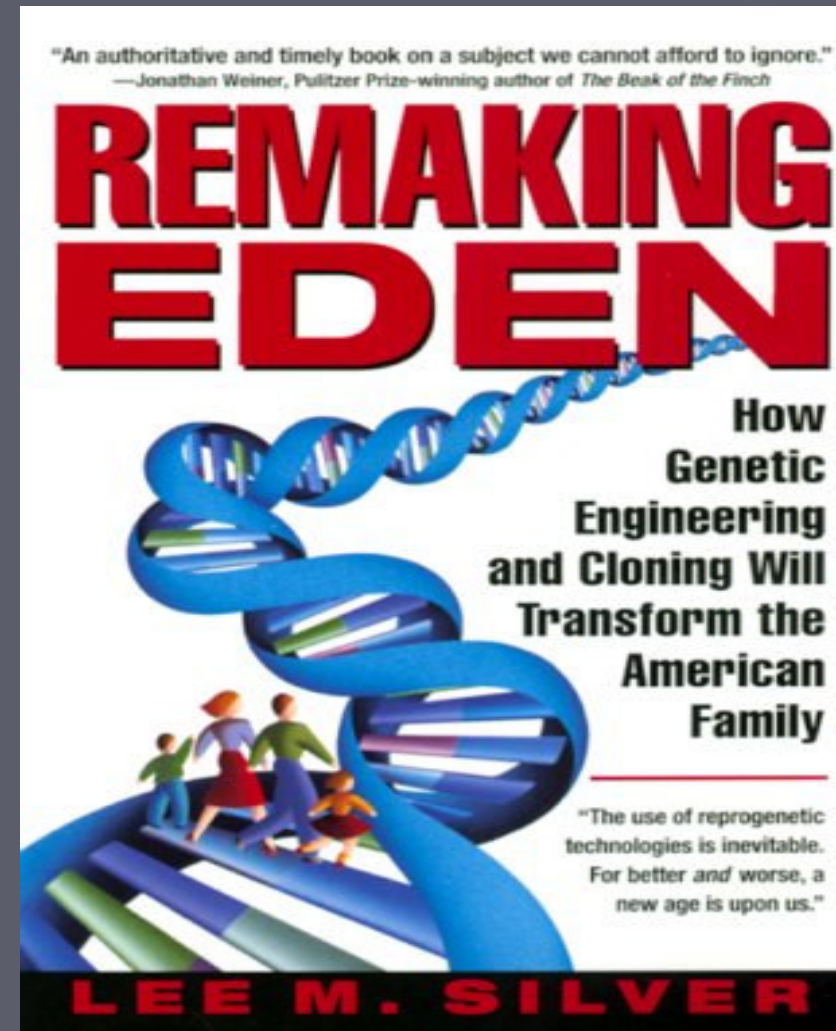
- Developing without critical dialogue
 - Organized scientific and biotechnology industry
 - No organized social justice, health, women's health, disability or LGBTQ perspectives or political power
- Market driven – commercialization of science & health
- Polarized political environment -- science v. religion
- Developing in a social, political and economic context of inequality and discrimination -- they can replicate or exacerbate existing inequality & create new forms

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...

...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





"Some will hate it, some will love it, but biotechnology is inevitably leading to a world in which plants, animals and human beings are going to be partly man-made.... Suppose parents could add 30 points to their children's IQ. Wouldn't you want to do it? And if you don't, your child will be the stupidest child in the neighborhood."

Lester Thurow, Professor of Economics and Management, Massachusetts Institute of Technology, *Creating Wealth: The New Rules for Individuals, Companies and Nations in a Knowledge-Based Economy* (New York: Harper Collins, 1999), page 33



"What is called for here is not genocide, the killing off of the population of incompetent cultures. But we do need to think realistically in terms of the 'phasing out' of such peoples . . . Evolutionary progress means the extinction of the less competent."

Richard Lynn, University of Ulster, Interview in *Newsday* (January 9, 1994)



"The right to a custom made child is merely the natural extension of our current discourse of reproductive rights. I see no virtue in the role of chance in conception, and great virtue is expanding choice....If women are allowed the 'reproductive right' or 'choice' to choose the father of their child, with his attendant characteristics, then they should be allowed the right to choose the characteristics from a catalog."

James Hughes, bioethics consultant, Secretary of the World Transhumanist Association, in "Embracing Change with All Four Arms," *Eubios Journal of Asian and International Bioethics* (Vol. 6, No. 4, June 1996), pages 94-101

The Political Questions



NOT whether technology is good/bad, allowed/banned, moral/immoral, science/religion, pro-choice/anti-choice

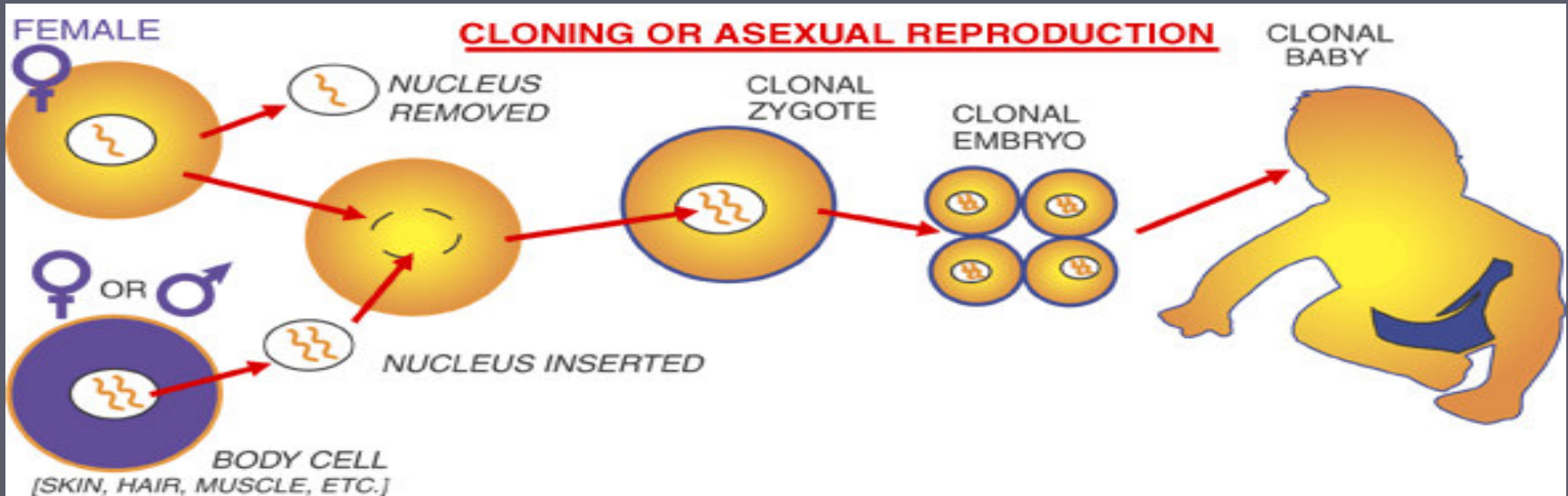
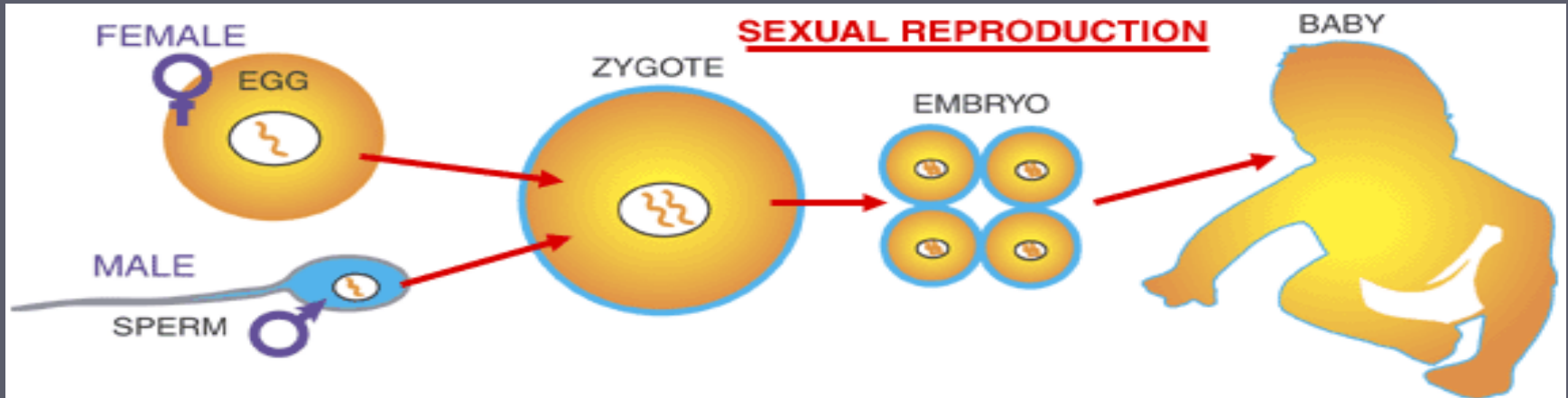
- What are the risks/benefits in the use of technology? Who benefits, who doesn't? Who is at risk?
- What is the balance to strive for between collective, social justice and personal liberties/individual choices?
- What mechanisms do we want to allocate resources and ensure health and safety? The government OR the market ?
- Who should be included in the decision-making process?

Making the Connections

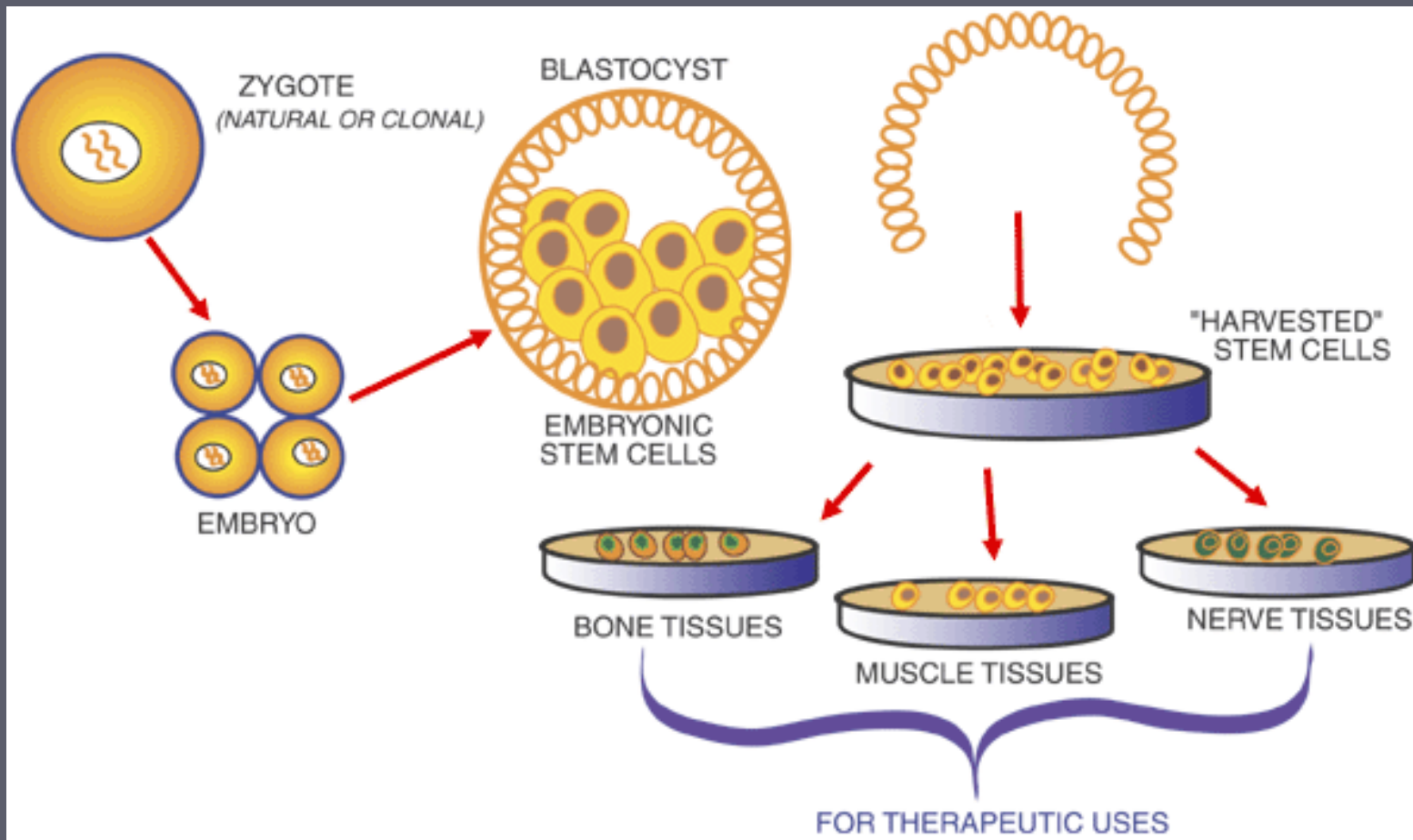


- Technologies
- Issues
- Relationships
- Movements

Cloning



Embryonic Stem Cells



Stem Cells



- Adult stem cell therapies – **GOOD!**
- Embryonic stem cell therapies w/ leftover IVF embryos – **GOOD!**
- Somatic cell nuclear transfer – **CAUTION!**
 - Cloning technology -- research cloning
 - # of fresh women's eggs
 - Expensive and individualized therapies

Eggs for research



Which comes first – the egg or the cure?

It could happen to you or your loved one:

- Diabetes
- Heart Disease
- Spinal cord injuries
- Parkinson's disease
- Blindness
- Strokes, AIDS, MS, cancer, among others

Thousands of Americans die everyday
from diseases that could potentially be
treated - or even cured - using stem cells

Women 21-35 years old needed
to donate eggs for stem cell
research project.

*(All procedures will be carried out at an accredited clinic by certified
medical professionals. Travel, hotel and other expenses covered)*

LET YOUR EGGS BE PART OF THE CURE!

Please donate your eggs. Call 202-315-3736

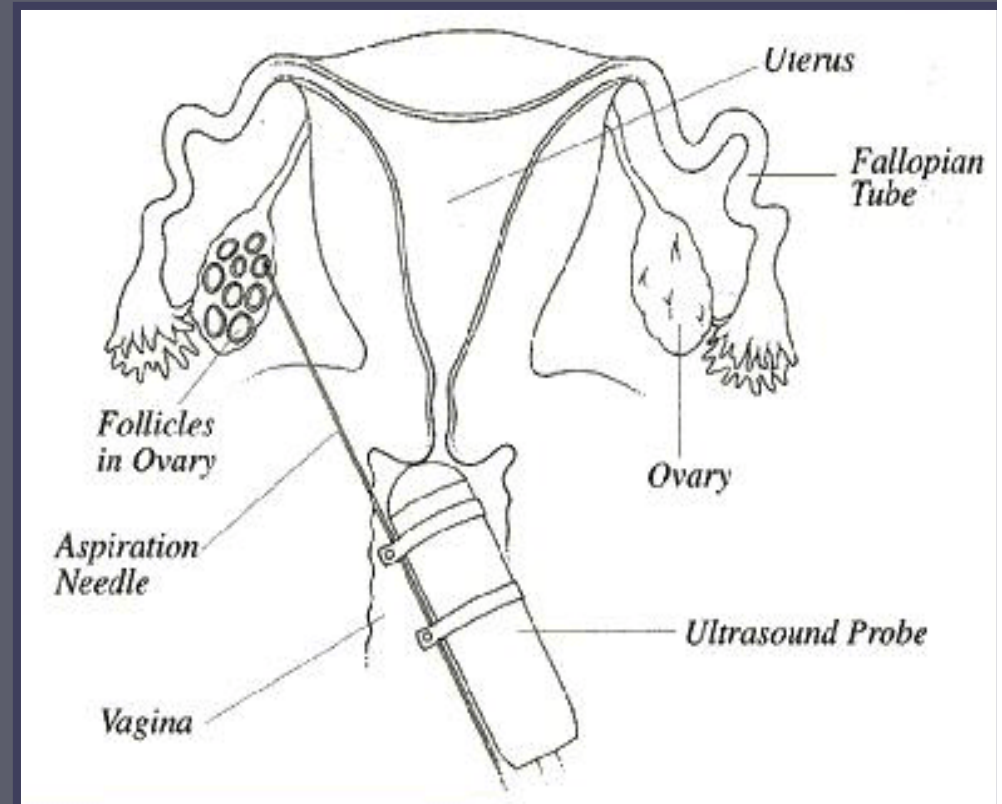
Current state of technology:

- Large number of eggs will be needed
- South Korea research scandal
 - Hwang said used 427 eggs; actually used 2,230
 - Involved ethical breaches
- CA SB 1260 – basic safeguards for women's health -- informed consent, women as research subjects

Egg extraction



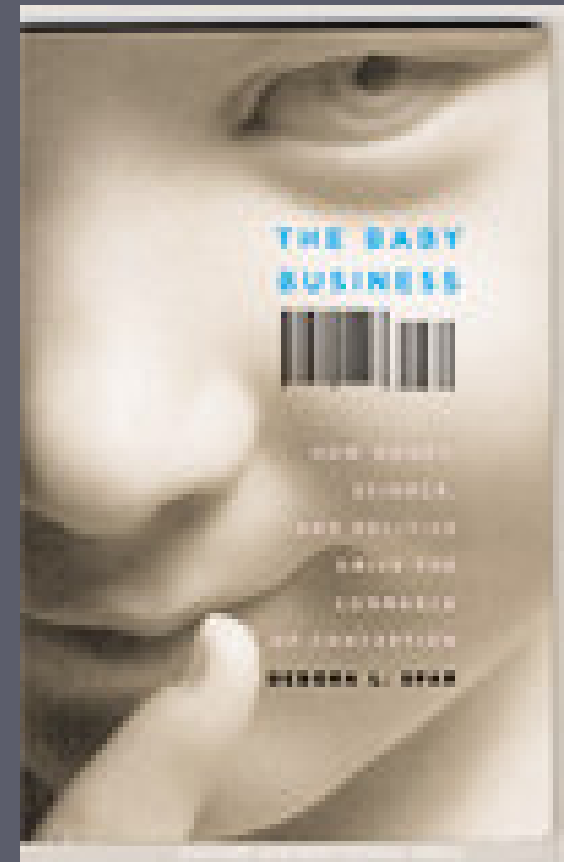
- Hormones used to “shut down” and “hyperstimulate” women’s ovaries to produce multiple eggs
- Adverse short-term health reactions
- No data on long-term health risks to women



Assisted Reproductive Technologies



- Benefits -- expands family formation options for many
- Concerns
 - Accessibility & equity (basic health care)
 - Unregulated in terms of health & safety – lack of data and oversight
 - Reproductive tourism & international markets – renting 3rd World wombs, egg market
 - Geneticizes family formation and ties



Recruiting egg “donors” for IVF



“EGG DONOR NEEDED: Professional warm couple looking for that special lady to help them create their family. Caucasian/Spanish background. Applicants must be in good health and top genetic makeup. Intelligent (SAT 1200+), dynamic, friendly, physically fit and physically attractive.”

Help
infertile
couples
experience
the joys of
parenthood
and earn up
to \$50,000


**BECOME
AN EGG
DONOR**

We need healthy women
up to age 32.
**Compensation begins
at \$5,000!**

For more information,
please contact Liz at
(703) 698-3909 or via email
at eggdonor@givf.com.

To apply online, visit
www.gametedonors.com.

Confidentiality assured


GENETICS & IVF
Institute

UCLA campus newspaper

Washington Express

Demand for Women's Eggs



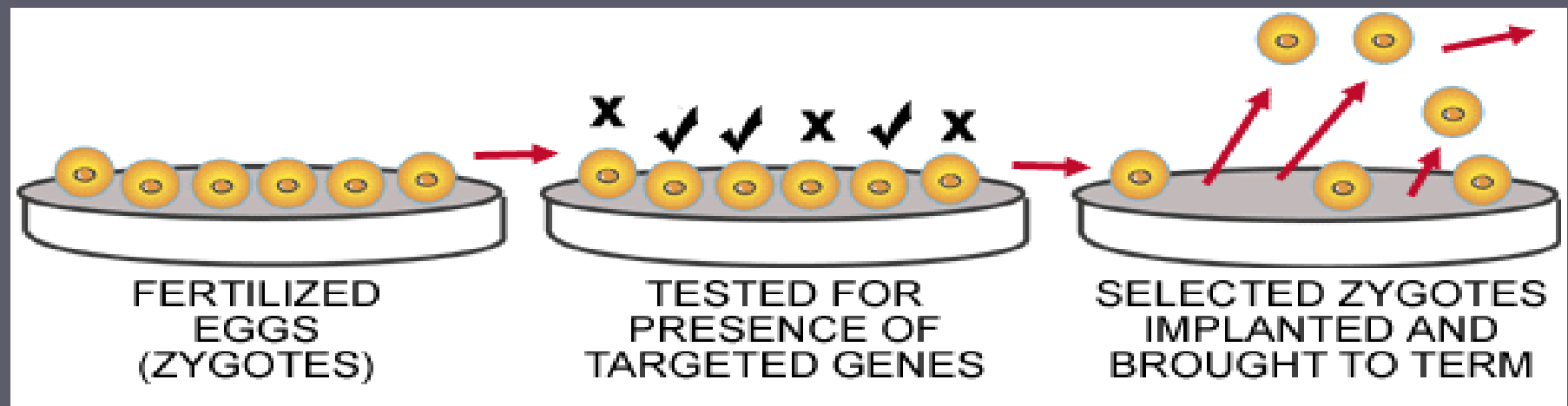
- **Eggs for fertility**
 - Recruitment in college newspapers; target young women
 - \$5,000-7,000/cycle; up to \$100,000 for “ivy-league” eggs
 - Reproductive tourism and international markets – Asia and Eastern Europe
- **Eggs for research (SCNT)**
 - 2,230 eggs for failed research in S. Korea
 - Eggs as the raw materials of research
 - No data on long-term health impacts (risk/benefit)
 - Compensation?

Pre-pregnancy selection technologies



Pre-implantation genetic diagnosis (PGD)

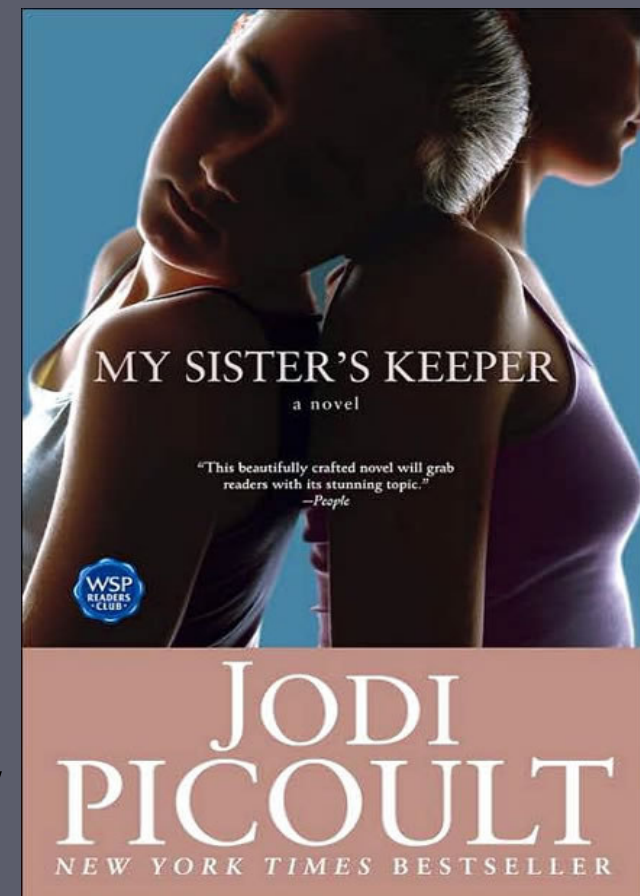
- In-vitro egg fertilization
- At day 3 (8 cells) a cell is extracted for testing
- Only selected (desired) embryos implanted



Pre-implantation genetic diagnosis (PGD)



- Developed for genetic “disability” de-selection
- More recently –
 - Sex selection
 - Late (adult) on-set diseases –
 - Alzheimer, diabetes
 - Tissue match for existing child needing transplant
- Normalizes genetic selection and desirability - “family eugenics”
- Reinforces medical model of disability



Pre-pregnancy selection technologies



- MicroSort® -- sorts sperm cells carrying Y-chromosome (male) from X-chromosome (female)
- Ads in *NY Times* and in-flight magazines
- ASRM ethical guidelines – discouraged for social sex selection
- Coming from India & China to U.S.

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



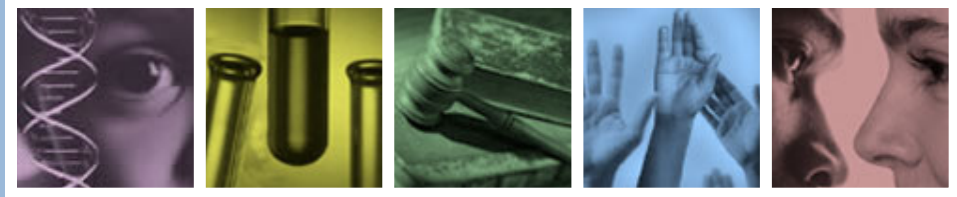
Gender Monitor



- At 5 weeks test the mother's DNA to determine sex of fetus
- Results via internet
- “For the woman who can't wait to open her Christmas gifts” and “Family fun”



Technologies on the horizon



Non-inheritable genetic modification
changes genes in cells except sperm and egg cells
-- gene therapy, gene transfer, gene doping

Inheritable genetic modification
changes genes in sperm and egg cells, or early embryos *-- designer baby technology, germline engineering*

SCIENCE

Designer Babies

Scientists say that, with gene therapy, they may soon be able to cure a child's inherited disease before he is even born. But should they be allowed to create kids with made-to-order traits? BY SHARON BEGLEY

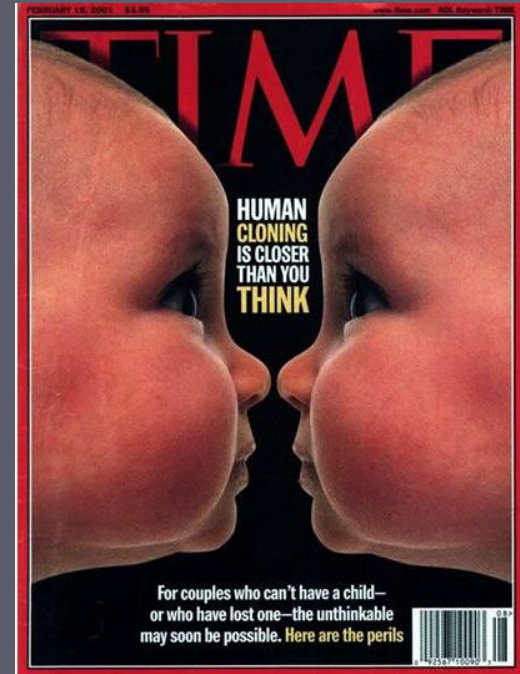
IT IS ONLY A MATTER OF TIME, ONE day—a day probably no more distant than the first wedding anniversary of a couple who are now teenage sweethearts—a man and a woman will walk into an in vitro fertilization clinic and make scientific history. Their problem won't be infertility, the reason couples now choose IVF. Rather, they will be desperate for a very special child, a child who will elude a family curse. To create their dream child, doctors will fertilize a few of the woman's eggs with her husband's sperm, as IVF clinics do today. But then they will inject an artificial human chromosome, carrying made-to-order genes like pearls on a string into the fertilized egg. One of the genes will carry instructions ordering cells to commit suicide (graphic). Then the doctors will place the embryo into the woman's uterus. If her baby is a boy, when he becomes an old man he, like his father and grandfather before him, will develop prostate cancer. But the cell-suicide gene will make his prostate cells self-destruct. The man, unlike his ancestors, will not die of the cancer. And since the gene that the doctors gave him copied itself into every cell of his body, including his sperm, his sons will beat prostate cancer, too.

Genetic engineers are preparing to cross what has long been an ethical Rubicon. Since 1990, gene therapy has meant slipping a healthy gene into the cells of one organ of a patient suffering from a genetic disease. Soon, it may mean something much more momentous: altering a fertilized egg so that genes in all of a person's cells, including eggs or sperm, also carry a gene that scientists, not parents, bequeathed them. When the pioneers of gene therapy first requested government approval for their experiments in 1987, they vowed they would never alter patients' eggs or sperm. That was then. This is now. One of those pioneers, Dr. W. French Anderson of the University of Southern California, recently put the National Institutes of Health on notice. Within two or three years, he said, he would ask approval to use gene therapy on a fetus that has been diagnosed with a deadly inherited disease. The therapy would cure the fetus before it is born. But the introduced genes, though targeted at only blood or immune-system cells, might inadvertently slip into the child's egg (or sperm) cells, too. If that happens, the genetic change would affect that child's children unto the nth generation. "Life would enter a new phase," says biophysicist Gregory Stock of UCLA, "one in which we seize control of our own evolution."

Judging by the 70 pages of public comments NIH has received since Anderson submitted his proposal in September, the overwhelming majority of scientists and ethicists weighing in oppose gene therapy that changes the "germline" (eggs and sperm). But the opposition could be a

What, me worry? DNA tricks may ease ethical concerns about 'playing God'

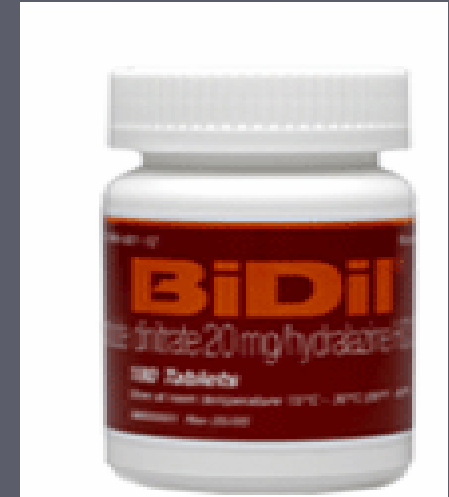
Cloning



Geneticization of race & health



- First race-based medicine
-- BiDil for African American heart disease
- Geneticization of health disparities and race -- encoding social identities in to genes



Re-biologicalization of difference



- Geneticization of race
- Geneticization of family ties
- Geneticization of health disparities
- Genetic/technological fixes for social/ environmental problems
- Increasing use of genetics to explain/justify differences:
 - Intelligence
 - Sexuality
 - Race

Women



- Pressures for “perfect” babies or specific types of babies
- Increasing demand for women’s eggs and reproductive materials -- health & safety risks, economic pressures
- Increased medicalization -- less control of one’s reproductive decisions & experiences --”Good Mothers”
- Who is “choosing” in the marketplace and at what cost to women and society?

Social Justice Concerns



- Reproductive health, rights and justice of women
- Health equity, access and priorities – “designer medicine” v. universal health care for all
- Geneticization of difference and family relations
- Reproductive tourism and markets -- international
- Lack of oversight, regulation and civil society debate
- Potential technological, market-based eugenics – breeding better people and disability eugenics – “perfect” babies or “designer babies”

Strategies



- Relationships are key – safety for hard debates
- Never alone and all important: always disability, race, gender, class, sexual orientation, environment, economics
- Understanding, not agreement
- Cross-movement discussions
 - Pre-implantation genetic diagnosis
 - Privacy and “choice”
 - Eugenics
- Coalition-building – social justice agenda

Multi-movement Model (& test case)



- Retreat at Asilomar
 - Reproductive Rights, Racial Justice, Economic Justice, Civil Rights, Disability, Queer Rights
 - Relationship Building
 - Safe spaces for complex & hard conversations
 - Personal Caucuses
 - Organizational Caucuses
 - Deal Breakers

Multi-movement



Personal Caucuses

- Black Women
- Indigenous Women
- Women with Disabilities
- Queer Women
- “Socially Infertile”
- Concerns for Future Generations

Organizational Caucuses

- Reproductive Rights
- Civil Rights/Progressive Politics
- Environmental Justice
- Disability Rights
- Health Service Providers
- Human Rights
- Queer Rights
- Health Disparities

Deal Breakers



- Restrict abortion, post-implantation choice
- Restrict access to family formation technology
- “You can’t be a parent/have a family”
- Ban on any technologies -- bad guys ban, we don’t
- Precautionary principle
- Restrictions without sufficient/compelling scientific data
- Framed only as a medical model of disability
- Elevate the moral status of the embryo
- Jeopardize choice and autonomy for women

Outcomes



- Together, face-to-face completely changed the discussion
- Not abstract, but real and difficult conversation and debate
- Automatic shift from medical to social model
- Shift from scientific, economic & ethical to social justice and political
- Required listening and changing perspectives

- Commitment to Coalitional work to set the social justice agenda on Assisted Reproductive & Genetic Technologies

Envisioning a Path to Justice



- Ask the political questions – not just scientific, economic or ethical questions
- Engage civil society, not just the experts
- Make the social justice connections concretely in practice, not abstractly
- Build relationships, be in the room and at the table
- Create safe spaces to have the difficult conversations
- Commit to working together
- Multi-movement coalition building work