Sex and Drugs in the Gene Age: Promoting a Reproductive Justice and Public Health Approach to Policy











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Outline



- Public health and reproductive justice frameworks
- Concerns about new reproductive and genetic technologies
- Overview of technologies
- Domestic regulation
- Role for public health professionals

Frameworks



Public Health

- Focus on populations rather than the individual
- Use social and biological reasoning to assess population distributions of disease and social inequalities in health. ~ Ecosocial Theory (Krieger)
- Multiple-level intervention: individual, environmental, and social (institutions and policy). ~ Ecological Theory

Reproductive Justice

- Physical, mental, spiritual, political, economic and social well-being of women and girls
- Requires economic, social and political power and resources to make healthy decisions for self, families, and communities in all areas of life.
 Asian Communities for Reproductive Justice

Public Health and RJ Concerns about NRGTs









- Health equity and access
- Lack of oversight and regulation:
 - Safety for women, children, and communities
- Privatized, individualized technologies
 - Trend of "geneticization"
 - Focus on individuals rather than underlying socio-economic problems
- Deepened health disparities and inequities: new forms of inequality
- Market-based eugenics: breeding "better" people
- Exploitation of women and commodification of their bodies

Focus on Genetics vs Social/Environmental Factors









- Geneticization of health disparities
- Increased use of genetics to explain/justify differences:
 - Intelligence
 - Sexuality
- Technological fixes for social, political and environmental problems
 - Crime
 - Violence
 - Alcoholism
 - Obesity
 - Mental illness
 - Shyness

Overview of NRGTs



- Assisted Reproductive Technologies (ART)
- Selection technologies
- Embryonic stem cell research
- Egg retrieval
- Race-based medicine
- Genetic modification and reproductive cloning

Assisted Reproductive Technologies (ART)



Treatments and procedures involving the handling of human eggs and sperm to establish a pregnancy:

- In vitro fertilization (IVF)
- Manipulation of sperm or eggs (ICSI, assisted hatching)
- Egg and sperm donation
- Freezing sperm, eggs, and embryos
- Alternative Insemination
- Hormonal drugs to stimulate egg production
- Surrogacy: gestational or genetic
- Accompanying genetic screening technologies

Assisted Reproductive Technologies (ART)



Benefits

- Expands family formation options
- Enables people to have genetically related children who otherwise couldn't:
 - Infertile women and men
 - Single women
 - —LGBTQI individuals and couples

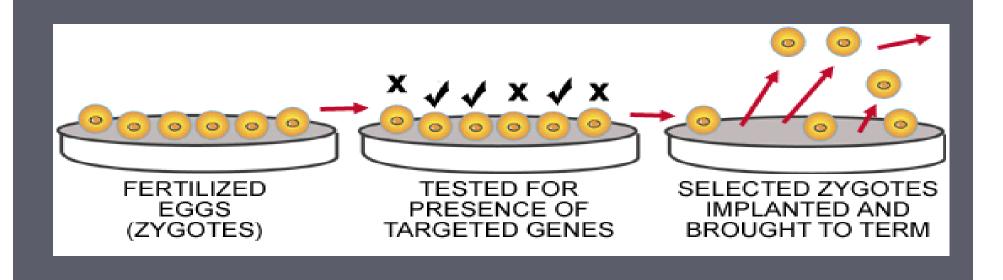
Concerns

- Accessibility and equity
- Limited health and safety regulation
- Lack of data and oversight
- Reproductive tourism

Pre-implantation Genetic Diagnosis (PGD)



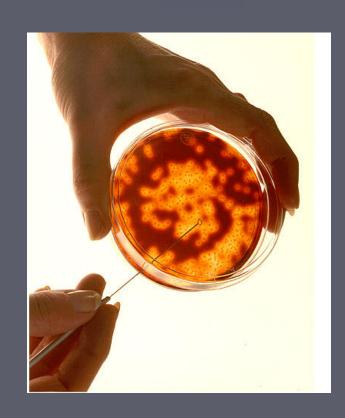
- Using in-vitro fertilization, eggs are fertilized
- At day 3 (8 cells) a cell is extracted for testing
- Only selected embryos implanted



Pre-implantation Genetic Diagnosis (PGD)



- Developed to select against genetic disabilities or medical conditions
- More recently
 - Sex selection
 - Late (adult) on-set diseases
 - —Alzheimer, diabetes
 - "Best" embryos, not healthy embryos
- Not allowed in a number of countries for certain selection like sex; regulated in other countries; unrestricted in the U.S.



Pre-conception Sex Selection



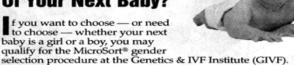
MicroSort ® -- sorts sperm cells carrying Y-

chromosome (male) from X-chromosome (female)

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Now available in New York and other metropolitan areas through collaborating physicians. Call for details. Caution: This procedure uses an investigational device investigational device uses an investigational

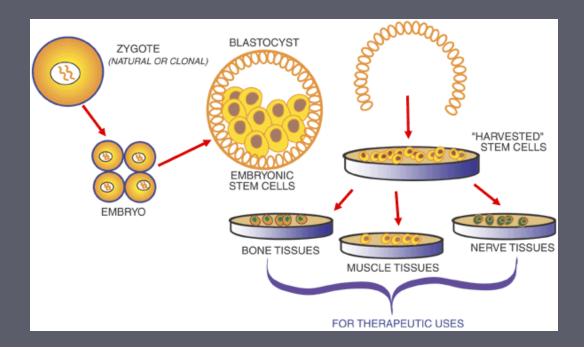
GENETICS & IVF INSTITUTE



Embryonic Stem Cell Research



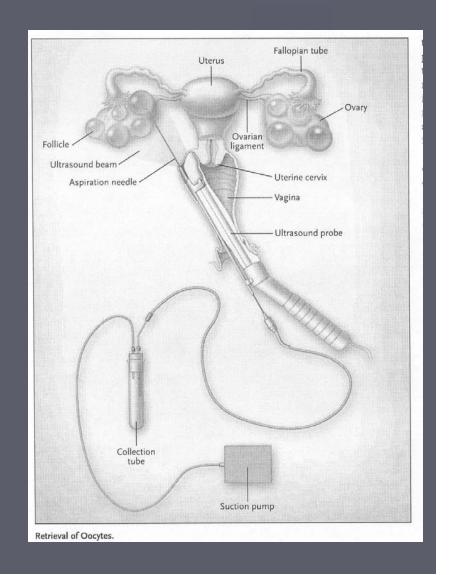
- Using leftover IVF embryos (all existing stem cell lines from this method)
- Using fresh eggs: research cloning (SCNT): not successful yet



Egg Retrieval Process for Fertility and Research

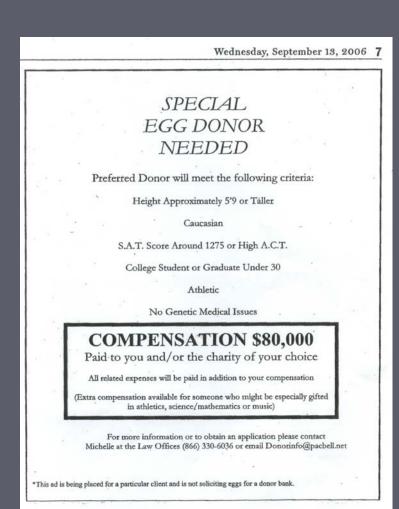


- Hormones used to "shut down" and "hyperstimulate" women's ovaries to produce multiple eggs
- Surgery under light anesthesia
- Some adverse health Reactions (OHSS)
- No data on long-term health risks



Egg "Donation" for Fertility







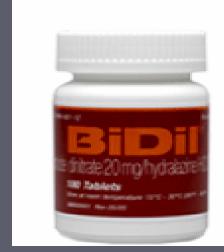
Chinese Donor - Urgent! Young Chinese Egg Donor Needed. Remuneration: \$100,000.00 and Negotiable. Loving & Caring Chinese Family is looking for healthy, young (under 32), highly intelligent, Chinese egg donor.

Geneticization of Race & Health



- First race-based medicine
 - -- BiDil for African Americans w/heart disease

 Geneticization of health disparities and race

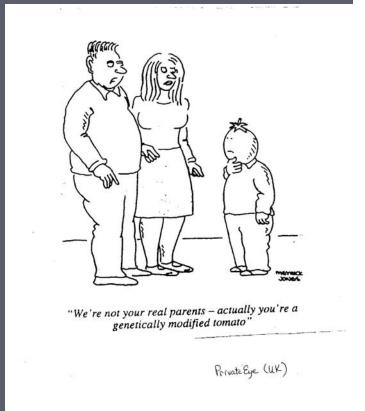




Possible Future Technologies



- 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
- Reproductive cloning: cloning humans



Federal Regulation (US)



- IVF clinics have to report success rates and source of eggs
- No other regulation of ART beyond general regulations on medical procedures/professions

No legislation on PGD, IGM, human cloning

State Regulation (US)



- 4 states have some regulation of ART: standards of clinics (LA, NH), who can receive ART (NH), regular reporting (PA), disclosure form to patients w/stats on clinic (VA)
- Patchwork of laws on human embryonic stem cell research (hESCR)
- SB 1260 (CA, 2006): eggs for research
- S 2039 (MA, 2005): hESCR and IVF, includes provisions on eggs for research and IVF

Professional Regulation (US)



- ASRM (American Society for Reproductive Medicine)
 - Voluntary guidelines
 - No enforcement/repercussions
 - Topics addressed:
 - —Compensation for egg donors
 - —Number of cycles of egg retrieval
 - -PGD
 - —Pre-conception and pre-implantation sex selection
 - —Research cloning
 - —Human cloning

Role for Public Health Community



- Raise ethical questions regarding new technologies based on public health and reproductive justice values and principles:
 - Are these technologies safe for women and children?
 - What are the risks/benefits in the use of technology?
 - Does the right to have/not have children mean there is a right to choose the characteristics of a child?
 - Do the technologies contribute to the devaluing of people with disabilities?
 - Do they increase reproductive choices or increase reproductive control by the medical system?
 - How do we balance population health and individual autonomy?

Role for PH Community (cont)



- Assess potential for these technologies to deepen health inequities
- Advocate for affected groups to be part of policy-making process
- Promote public health policy that ensures health and safety of those who use the technologies
- Engage in national conversations about what role the government should play in regulation and oversight
- Ensure that technologies developed and used benefit humanity and not one group at expense of any other