Gender and Justice

ASSISTED REPRODUCTIVE TECHNOLOGIES: OVERVIEW AND PERSPECTIVE USING A REPRODUCTIVE JUSTICE FRAMEWORK

INTRODUCTION

Assisted reproductive technologies (ART) have enabled millions of people in the world to have biological children who otherwise would not have been able to do so. According to the European Society for Human Reproduction and Embryology, more than three million babies have been born using ART worldwide in the last 30 years, enabling infertile women and men; single women and men; and lesbian, gay, and transgender couples to form genetically-related families. These new technologies have transformed the way we view reproduction. While they have created new hopeful possibilities, they also require that we pay attention to issues of health, ethics, law, and policy. Key concerns include: lack of access; health effects on women and children; potential for devaluation of the lives of people with disabilities; limitations on use by lesbian, gay, bisexual, transgender, questioning, and intersex (LGBTQI) individuals and couples; dangers of selecting characteristics of children; the commercial environment surrounding ART; and the nature of regulation in the US and other countries.

The Gender, Justice, and Human Genetics Program (G&J) of the Center for Genetics and Society has written this document to 1) provide basic background information on ART and 2) offer our allies a perspective on ART using a reproductive justice framework. While G&J is concerned with the health and rights of all communities, this document is primarily intended for use within the reproductive health, rights, and justice movements and therefore focuses largely on women. We hope that this document will contribute to building a foundation from which to promote ART policies that reflect social justice and human rights values and principles.

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SOCIAL JUSTICE AND HUMAN RIGHTS AS FOUNDATIONS OF G&J PROGRAM

The G&J Program works to build and deepen the interest and capacity of social justice constituencies to engage with new human genetic and reproductive technologies. The Program works in collaboration with allied organizations at the state and national levels to safeguard and expand the human rights, equality and health of women, LGBTQI communities, people with disabilities, and communities of color in an age of human biotechnology.

We recognize the impact that economic, social, and political factors have on women's abilities to make healthy decisions about their bodies, lives, families, and communities. In general, women need access to sustainable employment; quality education, health care, and child care; and safe home, work, and community environments. With regard to reproduction, women need to be in charge of their own fertility and have access to a wide range of safe and effective contraceptive and reproductive options. They need the resources necessary to ensure their health, including information and education, access to quality care, true informed consent, and products that are proven safe and effective. Women need to be centrally involved in setting research priorities and allocating resources. They need medical accuracy in the information they're given and access to medical advances that benefit humanity and not one group at the expense of another.

Within a social justice model, the G&J Program uses a reproductive justice framework, as conceptualized by SisterSong and Asian Communities for Reproductive Justice.¹ Reproductive justice extends beyond health services and information (reproductive health model) and fundamental liberties (reproductive rights model), to the economic, social, environmental, and political conditions that affect the health and lives of women and their families and communities. While reproductive health and reproductive rights work have achieved significant successes in promoting the health and rights of women, an accompanying broader framework is needed to address the full spectrum of factors impacting women's lives.

Reproductive rights advocates have been put in a particularly challenging position because public debate about ART has been dominated by abortion politics. The Religious Right has succeeded in centralizing the discussion on the moral status of the embryo, obscuring a broader set of issues. Put in a defensive position, the reproductive rights movement has, until recently, not had the opportunity to grapple internally with the complexities of ART use, and has tended to fall back on traditional models of individual autonomy and choice.

With increasing numbers of U.S. organizations shifting to a reproductive justice framework, much attention has recently been paid to the distinctions between reproductive health, reproductive rights, and reproductive justice models. The following are examples of goals that the reproductive health and rights movements would be likely to incorporate into their agendas, based on their respective models:

¹ See <u>http://www.sistersong.net/publications_and_articles/Understanding_RJ.pdf</u> and <u>http://reproductivejustice.org/download/ACRJ_A_New_Vision.pdf</u> for SisterSong and ACRJ's overviews of reproductive justice.

Reproductive health:

- Ensure that the technologies used are safe for women and children. Determine what additional research needs to be done to ensure safety.
- Advocate for public and private insurance coverage of ART.
- Ensure that ART information is accurate and that resources and services are culturally and linguistically competent.

Reproductive rights:

- Combat discrimination in access to reproductive technologies (e.g., clinics that don't allow/provide fertility treatments to lesbians and single women).
- Ensure access to comprehensive reproductive health care services and information, including reproductive technologies, for people of all incomes.
- Respect and protect a woman's right to make her own decision about childbearing, including use of reproductive and genetic technologies.

Currently ART is not included as part of broad-based reproductive health or rights agendas and, when it is addressed by individual organizations, it is usually with a focus on increasing access to the technologies and improving services and legal protections. While these objectives are important, they are located within an individual rights framework and do not address larger societal implications.

A reproductive justice model offers a perspective with which to address the complex issues posed by ART, in which individual autonomy and collective good do not need to be in conflict with each other. G&J has hosted numerous gatherings in California and around the country with social justice advocates to develop a reproductive justice analysis of new reproductive and genetic technologies. Our convenings, retreats, and roundtables have included:

- Designer Genes: Genetic Technologies and the De-selection of Queer Bodies in conjunction with the New York Lesbian, Gay, Bisexual and Transgender Community Center and the Committee on Women, Population and the Environment (NY, NY May 2006)
- Assisted Reproductive and Genetic Technologies: An Intimate Retreat to Explore and Envision the Path to Justice in conjunction with Planned Parenthood Federation of America (Pacific Grove, CA, October 2006)
- *Genetics and Justice: Implications of New Reproductive and Genetic Technologies for Women of Color* in conjunction with the Pacific Institute for Women's Health and cosponsored by Black Women for Wellness, the California Black Women's Health Project, California Latinas for Reproductive Justice, the Latino Issues Forum, the National Health Law Program, the Pro-Choice Alliance for Responsible Research, the Reproductive Justice Coalition of Los Angeles, and the Women's Foundation of California (Los Angeles, CA, November 2006)
- *Reproductive Rights and Justice Retreat On the Ethics, Politics and Policy of New Reproductive and Genetic Technologies* in conjunction with the ACLU of Northern California (Pacific Grove, CA, September 2007)
- Roundtables discussions with a small group of disability rights and reproductive rights and justice advocates (Quarterly, beginning February 2007)

These events, in which we discussed concerns, values, principles, and policy, have led the G&J Program to articulate an initial set of goals related to ART using a reproductive justice framework:

Reproductive justice:

- De-criminalize the reproductive decisions of women.
- Prevent eugenic outcomes for society.
- Oppose policies that devalue the lives of people with disabilities.
- Require high industry standards for health and safety of ART.
- Support equal access to ART, particularly for people with disabilities, women of color, LGBTQI individuals and couples, and low-income women.
- Advocate for policies that affirm family formation for people with disabilities and LGBTQI individuals and couples.
- Ensure access to the information necessary to make informed choices.
- Direct resources toward environmental causes of infertility and addressing the disproportionate rate of infertility among women of color.
- Integrate an intersectional analysis and a human rights framework into work on ART issues.
- Conduct advocacy in partnerships and coalitions with organizations and their constituencies, and involve those who use and are affected by ART.

Work with our allies using a reproductive justice framework has moved us toward asking the following ethical, social, and political questions:

- Are these technologies safe for women and children? Who should be responsible for ensuring their safety?
- Do ART technologies increase or decrease reproductive choices and individual control over decision-making?
- Does the right to have/not have children mean there is a right to choose the characteristics of a child?
- Do new reproductive and genetic technologies contribute to the devaluing of people with disabilities?
- Do they increase exploitation of young women, economically vulnerable women, and communities of color?
- Do they increase commodification of women's reproductive capacity and reproductive tissue?
- Should we draw lines for how certain technologies can be used (e.g., pre-implantation genetic diagnosis² for medical and not social purposes)?³

² Preimplantation genetic diagnosis (PGD) involves screening embryos created through in vitro fertilization for the presence or absence of certain genes, such as de-selecting for a disability or selecting for a particular sex.

³ Some make the distinction that medical screening (for genes that show the presence of disease or medical conditions, e.g., Tay-Sachs, sickle cell anemia, spina bifida) is justifiable, but would not be for social traits such as eye color, skin tone, or intelligence. Others make the point that drawing lines between medical and social stems from the devaluation of the lives of people with disabilities, and that we would not make this distinction if people with disabilities were fully valued members of society.

- How do we focus attention on industry accountability rather than women's individual decisions?
- What role should the government play regarding regulation and oversight of ART?

A reproductive justice model offers an opportunity to make connections between the forces that shape women's opportunities, the conditions that affect women's decisions, and the societal impact of the availability and use of certain technologies and practices.

OVERVIEW OF THIS DOCUMENT

A necessary component in integrating a reproductive justice perspective on ART is ensuring that reproductive health, rights, and justice organizations understand what technologies are currently available and the context surrounding their use. This document provides basic background information on ART in an effort to increase discussion of the types of goals and questions listed above. The following issues are covered in this document:

- Background information on ART
 - Use of ART
 - Causes of infertility
 - Overview of current technologies
 - Health risks to women
 - o Impact on children
- Context of ART use
 - o Industry
 - Regulation
- Moving toward socially just ART policy
 - Next steps

BACKGROUND INFORMATION

USE OF ART

Motivation for using ART

People are motivated to use ART to have a genetically related child, and circumstances vary widely: couples in which one person is infertile;⁴ lesbian couples; gay male couples; a couple in which one or both partners are transgender; single straight, queer and trans women and men; women undergoing chemotherapy; women who want to delay childbearing; and couples who want to use pre-implantation genetic diagnosis (PGD) to screen against disability or for sex. As genetic screening becomes more popular, affordable, and able to test for a greater number of characteristics, it is possible that more people who are not infertile will use in vitro fertilization and PGD in order to select characteristics of their children.

⁴ A medical definition of infertility is the inability to become pregnant after a year of unprotected intercourse or the inability to carry a pregnancy to a live birth. Approximately 15% of women and 10-15% of men are infertile in the US.

Because the ART industry is largely unregulated, we have very little data on who uses these technologies. Until 2003, the only national data collected was through the Fertility Clinic Success Rate and Certification Act of 1992, which requires that fertility clinics report the number of pregnancies and live births from ART, which the Act defines narrowly as "fertility treatments in which both eggs and sperm are handled in the laboratory" (e.g., in vitro fertilization and related procedures) and excludes treatments such as fertility drugs or alternative insemination (also known as artificial insemination). The only demographic data collected is women's age.

In 2004, nine states⁵ began using the 2003 U.S. Standard Certificate of Live Birth, which included a checkbox in its risk factor section to indicate "pregnancy resulted from infertility treatment" and included ART as defined above *and* "fertility-enhancing drugs, artificial insemination, or intrauterine insemination." Analysis of the data from these seven states showed that 1% of all live births resulted from infertility therapies (consistent with national statistics), 90% of which were to white women.⁶

Accessibility

Access to ART is limited by cost and by discriminatory policies. Almost all ART is expensive and therefore only accessible to people who can afford it. No states' public benefits programs cover IVF. Some states require private insurers to cover ART, though this only applies to individuals who have a medical diagnosis of infertility (see footnote 4). Twelve states are mandated to cover,⁷ and 2 states are mandated to offer⁸ coverage. Specifics on coverage depend on the state. Some states exempt HMOs or companies with few employees. Other states offer lifetime limits to their coverage (Arkansas, \$15,000) or limits on the number of cycles allowed (Connecticut, four cycles; Hawaii, one cycle). Connecticut is the only state that limits the number of embryos that can be transferred under insurance coverage (two embryos per treatment cycle).⁹

In California, group health insurers covering hospital, medical or surgical expenses must let employers know infertility coverage is available.¹⁰ However, the law does not require those insurers to provide the coverage; nor does it force employers to include it in their employee insurance plans, and IVF is exempt from the plan.¹¹ Because the state plans only apply to those who are medically diagnosed with infertility, many others who want to use ART (e.g., lesbian, gay, and trans couples, and single people) are excluded.

⁵ Florida, Idaho, Kentucky, New Hampshire, New York (excluding New York City), Pennsylvania, South Carolina, Tennessee, and Washington.

⁶ Martin JA, Menacker F. (2007). Expanded health data from the new birth certificate. *National Vital Statistics Reports 2004*, 55(12). Retrieved from the National Center for Health Statistics http://www.cdc.gov/nchs/data/nvsr/nvsr55/nvsr55_12.pdf

⁷ Insurers must provide some level of fertility treatment benefit in every policy and include the cost in the policy premium. States with these laws are: Arkansas, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, Montana, New Jersey, New York, Oregon, Rhode Island, and West Virginia.

⁸ Insurers must offer coverage that employers may or may not choose to purchase. States are California and Texas.
⁹ Arons, J. (2007). *Future choices: Assisted reproductive technologies and the law.* Retrieved from http://americanprogress.org/issues/2007/12/pdf/arons_art.pdf

¹⁰ Retrieved from <u>http://www.resolve.org/site/PageServer?pagename=ta_ic_coverage</u>.

¹¹ Coverage doesn't include IVF but includes fertility-enhancing drugs or diagnosis, diagnostic testing, medication, surgery, and Gamete Intrafallopian Transfer (GIFT).

Another critical barrier to access is discrimination by state laws or fertility clinics. Coverage in five of the states with insurance mandates¹² is only available to married couples, and four of these states¹³ mandate use of the husband's sperm, eliminating the possibility of donor sperm. Some fertility clinics only offer services to married couples as well. The American Society for Reproductive Medicine reports that fertility clinics vary in their willingness to treat single women, single men, lesbian couples, and gay male couples.¹⁴ The Benitez case, currently¹⁵ before the California Supreme Court, involves a woman who was denied infertility treatment by two doctors at a fertility clinic because she is a lesbian, and is the first case of its kind to be heard by the courts. Discriminatory policies embedded in state laws, policies of individual fertility clinics, and clauses that allow individual physicians to "opt out" of treating certain people create additional barriers beyond economic challenges.

CAUSES OF INFERTILITY

For those using ART because of medical infertility, there are a variety of factors that can contribute to this diagnosis. According to the Collaborative on Health and the Environment, infertility can be caused by genetic or environmental factors, combinations of the two, or endocrine or immune system disorders. It can be caused in the womb, in which genetic instructions are impacted by factors such as a mutation, a chemical insult, or an imbalance in hormones and the impact is not seen until the individual tries to procreate; or it can be caused in adulthood. 20-40% of infertility is due to male factors, 30% to female, and the remainder due to both partners or "unexplained." Aging is the most basic cause of infertility. Women are less likely to become pregnant as they become older, and success rates of fertility treatments decrease with age as well.

Female infertility is most often caused by problems with ovulation (40%) or fallopian tubes (40%). Other possible causes include endometriosis, in which the uterine lining grows outside the uterus, premature ovarian failure, in which a woman's ovaries stop functioning before she reaches the age of forty, and uterine fibroids. Women who were exposed in the womb to diethylstilbestrol (DES), a synthetic estrogen prescribed to women from 1938-1971, have had an increased risk of infertility.

Sexually transmitted infections (STIs) also play a major role in infertility. Chlamydia, for example, has one of the highest numbers of reported cases of STIs in the United States (930,000 in 2004, with three times higher rate for women than men). However, because the symptoms are mild, it often goes untreated and, in women, can develop into pelvic inflammatory disease (PID). PID is an infection of the uterus, fallopian tubes, and other reproductive organs, and if left untreated can damage reproductive tissues and cause infertility. According to the Centers for Disease Control (CDC), 10-40% of women with untreated Chlamydia will develop PID, of which 20% will become infertile. It is unclear whether Chlamydia can decrease male fertility, but

¹² Arons, J. Arkansas, Hawaii, Maryland, Rhode Island, and Texas.

¹³ Arons, J. Arkansas, Hawaii, Maryland, Texas.

¹⁴ The Ethics Committee of the American Society for Reproductive Medicine. (2006). Access to fertility treatments by gays, lesbians, and unmarried persons. Fertility and Sterility, 86, 1333-5. Retrieved from http://www.asrm.org/Media/Ethics/fertility_gaylesunmarried.pdf¹⁵ As of December 2007.

some studies have shown that it can affect sperm motility.¹⁶ Males with Chlamydia also put their female partners at risk of infection, PID, and possible infertility.

Environmental toxins, including exposure to lead, pesticides, and other chemicals, unquestionably affect fertility in men and women. Researchers have documented many examples, the strongest cases involving industrial and occupational exposures. These usually involve small numbers of people exposed to high levels of contamination. Links between infertility and everyday low-level exposure to toxins have been harder to document, but people are regularly exposed to toxins from pesticides (crop dusting), household products (baby bottles, children's toys, cleaners, cosmetics), and industrial production (including smoke). One study found that infertile women were 27 times more likely to have handled herbicides in the two years prior to attempting pregnancy than women who were fertile.¹⁷ Women of color experience a disproportionately high rate of infertility, due to lack of access to health care and health education (and therefore have higher rates of STIs and lower rates of treatment) and higher exposure to industrial and occupational toxins (refineries, pesticides, nail salons, dry cleaning). For men, environmental toxins have been shown to impact sperm count, motility, quality, and semen volume.

Other issues that have been known to contribute to infertility in women include stress, diet, exercise, and weight. Obesity contributes to infertility because it can cause irregular menstrual cycles and affect ovulation. Male infertility is most often attributed to low sperm count or abnormal sperm shape/structure. These conditions may be caused by health and lifestyle choices, including smoking, drinking alcohol, or taking recreational drugs or certain medications. Cancer treatments involving radiation and certain drugs can cause infertility in men and women as well.

It is unclear if rates of medical infertility are actually increasing or if numbers are higher because women are waiting longer to have children.

OVERVIEW OF CURRENT TECHNOLOGIES

ART encompasses a variety of technologies,¹⁸ some used to initiate pregnancy, and others more specifically used to increase likelihood of pregnancy and/or to test for the presence of certain genes so prospective parents can choose which embryos to implant after in vitro fertilization. There are three primary means of initiating pregnancy: alternative insemination (AI), prescription fertility-enhancing drugs, and in vitro fertilization (IVF). There is no available data on the number of overall ART procedures performed in the United States, only statistics on the number of IVF cycles and subsequent successful pregnancies and live births.¹⁹

¹⁶ Sperm motility refers to the percentage of moving sperm in a sample of semen. Good motility means that at least half of the sperm should be moving rapidly (MedicineNet.com).

¹⁷ Greenlee, AR, Arbuckle, TE & Chyou, P-H. (2003). Risk factors for female infertility in an agricultural region. *Epidemiology*, 14, 429-436.

¹⁸ There is no standard definition for ART. The World Medical Association does not include alternative insemination in its definition. The U.S. Center for Disease Control only includes technologies that involve the handling of both sperm and eggs in a laboratory, such as IVF. In this document, ART refers to all of the technologies listed in the Overview of Current Technologies section.

¹⁹ 2004 statistics (latest available) can be found at <u>http://www.cdc.gov/MMWR/preview/mmwrhtml/ss5606a1.htm</u>

Alternative Insemination (AI) (also known as Artificial Insemination)

AI refers to several different procedures, all of which involve inserting sperm into a woman's body, the differences referring to whether the sperm is placed in her vagina, uterus, cervix or fallopian tubes. AI can also be combined with hormonal drugs to stimulate production of multiple eggs to increase likelihood that one of them will be fertilized. AI can be done at home with a syringe or in a medical setting. Sperm used for AI is usually "washed," which separates the sperm from the semen and eliminates dead or slow sperm and other chemicals that may impair fertilization. Cost for the sperm depends on several factors: whether using free sperm (from partner, friend, etc.), sperm bought through a bank (\$200-500); whether doing intrauterine insemination (\$120-\$400) or intrafallopian insemination (\$1,000); and if using fertility drugs, ultrasound and blood work (up to \$5,000-6,000). If using a sperm bank, costs can also include registration and consultation, fertility awareness supplies, information about donors, and storage, packaging, and shipping. Success rates can range from 5-30%, depending on the age of the woman; whether drugs are used in conjunction with AI; if the sperm is inseminated vaginally or intra-uterine; if the sperm is washed or unwashed; and the quality of the sperm.

Fertility-enhancing drugs

Fertility drugs can be oral or injectible. The most common fertility drug used is clomiphene citrate (brand name Clomid or Serophene), which is taken orally to help women who are not ovulating or who ovulate irregularly to produce one or more mature eggs. Injectibles are called gonadotropins and stimulate the ovary to produce more follicles in one cycle. Clomiphene citrate and gonadotropins can be used on their own with intercourse, or combined with AI or IVF. Success rates depend on many factors, especially maternal age and the quality of the accompanying sperm. Clomiphene costs \$30-\$50 a month for the drug only, not including the cost of doctor visits, ultrasounds, or follow-up procedures such as AI. Gonadotropin injections cost \$2,000-\$5,000 a month, including doctors' visits and tests. Success rates range broadly, from 20-60%.

In vitro fertilization (IVF) and related or accompanying procedures

IVF and related treatments (GIFT and ZIFT, see below) are the most invasive ART treatments. Usually women try other methods first, and turn to IVF when those methods have not succeeded in pregnancy or live birth. One percent of babies in the US are born using IVF. Unlike AI, fertilization takes place *outside the woman's body* in which eggs (retrieved from the woman trying to get pregnant or from an egg donor) are fertilized with sperm (from a partner or donor) in a Petri dish. Current egg retrieval practice involves ovarian stimulation drugs to produce multiple eggs and surgery under light anesthesia (see "egg retrieval" below). Costs range from \$10,000-14,000 per IVF cycle, and most women need to go through multiple cycles. Success rates depend on many factors, but average is 34% successful pregnancies per cycle.

GIFT and ZIFT (variations of IVF):

Zygote Intrafallopian Transfer (ZIFT) and Gamete Intrafallopian Tube Transfer (GIFT) are variations of IVF, used much less often (only 2% of the time, compared to 98% for IVF). They both begin with ovarian stimulation drugs and surgical egg retrieval. With ZIFT, eggs are fertilized in a Petri dish and the resulting zygote(s) (a one cell embryo) is placed directly into the woman's fallopian tube through laparoscopic surgery (as opposed to IVF, in which an embryo is placed in the woman's uterus). ZIFT is used when a woman has problems ovulating, there is

significant male factor infertility, or other methods of treatment have been unsuccessful. It is not commonly used because it is considered one of the most invasive ART treatments. With GIFT, after hormonal stimulation and egg retrieval, eggs and sperm are both placed directly into the woman's fallopian tube, allowing fertilization to happen in the woman's body, rather than in a Petri dish. GIFT is used for women with unexplained infertility. The cost of ZIFT or GIFT ranges from \$12,000-20,000, and success rates are 5-10% higher than IVF.

Egg Retrieval

Women usually produce one mature egg per menstrual cycle. Because IVF is so expensive, current clinical practice is to give women hormonal drugs to stimulate multiple eggs in one cycle, to increase their chances of pregnancy. For this process, women inject three different hormones over the course of four to six weeks to "shut down" their ovaries, "hyperstimulate" them, and to control the timing that the mature eggs will be released. This is followed by a surgical procedure under light anesthesia, in which an ultrasound-guided needle is inserted through the vaginal wall into the ovary and the eggs are suctioned out. Eggs are then fertilized in a laboratory with sperm, and the resulting viable embryo(s) are implanted into the uterus of the woman intending to become pregnant. Eggs are retrieved from the woman undergoing IVF or, if she is not able to conceive using her own eggs, from a third party, known as an "egg donor."

Gamete Donation

People often turn to egg or sperm donors when they cannot use their own eggs or sperm to become pregnant, or when they don't have both sperm and eggs available to them, such as single women or people in LGBT relationships. They can go through a fertility clinic, an egg brokerage agency, a sperm bank, or recruit a known donor (friend, family member) or unknown donor (place Web or newspaper ad). Sperm donation can be used for AI, IVF, GIFT, and ZIFT; egg donation for all but AI. The term "donor" can be misleading as "donors" are often paid for their gametes.

Sperm donors are paid about \$75 per sample and egg donors anywhere from \$5,000 to \$100,000 per cycle. The process of collecting sperm and eggs is radically different, as the former involves masturbation only and no risk to the man, while the latter involves use of multiple drugs and surgery and involves some degree of risk. Of most concern is that we don't know the level of long-term risk for egg retrieval because not enough studies have been conducted.

The American Society for Reproductive Medicine (ASRM) recommends that egg donors go through no more than six cycles, but there is no legal limitation and no tracking of egg donors who go from one clinic or broker to another. Sperm donors at the California Sperm Bank are asked to commit for at least a year and donate at least once a week.

Cryopreservation is the process of slowly freezing bodily materials so that they can be used at a future date. In ART, this typically involves sperm or embryos, both of which can be successfully frozen. Egg cryopreservation, on the other hand, has proven much more difficult because eggs have high water content and the freezing process often leads to the formation of ice crystals, bursting the egg cells. The most common instances of egg cryopreservation have been for women undergoing chemotherapy who wish to retain their reproductive options post-treatment.

Vitrification is a new technique that freezes eggs so quickly that ice crystals are less likely to form.

Intracytoplasmic Sperm Injection (ICSI) involves manually injecting a single sperm into the cytoplasm (the material outside of the nucleus) of an egg. It is used when a man has a low sperm count, no sperm present in the ejaculate, low sperm motility, sperm that are abnormally shaped, or when IVF has previously been unsuccessful. It costs an additional \$1500 per IVF cycle, is used in more than 56% of IVF procedures, and has a 31% success rate.

Preimplantation genetic diagnosis (PGD) can accompany IVF, and tests the embryo for particular genetic traits, such as medical condition or sex. Cost is \$2500-\$5000 per cycle. PGD is done in 4-6% of all IVF procedures. Success rates are 90% for testing for medical conditions and close to 100% for sex selection.

Ooplasmic transfer involves egg retrieval from the woman undergoing IVF and another woman donating ooplasm (the cytoplasm of an egg cell: the material outside the nucleus). The egg is then fertilized with sperm and implanted into the woman intending to become pregnant. The resulting child has DNA from both women because of the mitochondrial DNA present in the ooplasm of the donor, as well as DNA from the sperm provider (partner or donor), and therefore has three genetic parents. It had been used for women whose infertility seemed to stem from the ooplasm in their eggs. In 2002, however, an FDA Advisory Committee held a public meeting to discuss ooplasm transfer procedures. A statement issued by the FDA at this meeting reported that at least two dozen births attributed to ooplasm transfer had been reported by three fertility clinics since 1998. The FDA expressed concerns about this technique, citing its potential to alter the germline (cells carrying genetic material from generation to generation), the medical risks associated with mitochondrial heteroplasmy,²⁰ the high incidence of Turner's syndrome²¹ in fetuses reported in one study (2 of 13 reported pregnancies), and the paucity of animal studies and other pre-clinical data. A general consensus was reached at the meeting that more preclinical data would be necessary before the FDA would allow further clinical trials involving ooplasm transfer to proceed.

Surrogacy is an agreement in which a woman becomes pregnant and gives birth to a child for someone else. Surrogacy can be paid or unpaid, and often involves a legal contract in which the surrogate gives up parental rights to the child she births. If the surrogate's own eggs are used through alternative insemination or IVF, she is known as the "genetic surrogate." If embryos are created using another woman's eggs and implanted in the surrogate, she is known as the "gestational surrogate" and has no genetic tie to the child. Hiring a surrogate in the US can cost \$40,000 to \$100,000, including the surrogate fee, insemination or IVF costs, and costs related to medical care, transportation, and legal services. Hired surrogates are paid an average of \$25,000. One percent of all IVF procedures in the US in 2004 used surrogates, because current practice is to implant multiple embryos to increase success rates in this very expensive endeavor. According

²⁰ Heteroplasmy is a mixture of recipient and donor mitochondrial DNA.

²¹ Turner's Syndrome is a chromosomal disorder in girls who have only one X chromosome. Physical symptoms include short stature, delayed skeleton growth, cardiovascular problems, absent or incomplete development at puberty, webbed neck, and infertility.

to the CDC's report from 2003, 74% of all reporting fertility clinics offer gestational surrogacy. Some couples hire women in developing countries to be surrogates for a much lower cost. Hiring a surrogate in India, for example, ranges in cost from \$5,000-\$12,000, and the surrogate gets paid \$3,000-\$6,000. (See more on "reproductive tourism" later in this document.)

HEALTH RISKS TO WOMEN

The level of risk for women using ART depends on the technology used. Women doing alternative insemination using donor sperm that has been screened for sexually transmitted infections (STIs) face virtually no risk from the procedure, beyond standard risks that any pregnant woman would face. Women undergoing egg retrieval for IVF, on the other hand, face short-term risks associated with taking hormones to stimulate multiple egg production, and the long-term health risks are still unknown.

Risks from egg retrieval

Fertility Drugs and Ovarian Hyperstimulation Syndrome

Ovarian Hyperstimulation Syndrome (OHSS) is the most well-studied side effect of hormonallystimulated egg retrieval, and is classified in mild, moderate and severe forms. Its reported incidence in severe form varies widely. One reason is that classifications of severe and moderate OHSS vary from study to study, creating an uneven field of results. The classifications of degrees of OHSS have been modified several times since the use of assisted reproductive techniques emerged in the 1960s.

According to a literature review, the rate of severe OHSS is about 1% but "one should be aware of its recent, progressive increase."²² In terms of IVF cycles, moderate OHSS occurs in about 3-6% of women undergoing treatment, while mild OHSS occurs in 20-33%. The fertility drug clomiphene is not usually responsible for severe OHSS, but has been found to have an 8% incidence rate of moderate OHSS. Additionally, younger women seem to have a higher risk of developing OHSS. This may be due to a higher density of gonadotropin receptors or a larger number of follicles in the ovaries of younger women. The risk of severe complications is higher among women with late-onset OHSS, which only occurs in women who become pregnant with their own fertilized eggs. Therefore egg donors have a lower risk of developing severe OHSS.

Lupron

Lupron is the drug most commonly used to shut down a woman's ovaries for IVF, allowing the doctor to control the timing of her ovulation. Lupron has never been approved specifically for use in IVF (it was approved by the FDA in 1985 for advanced prostate cancer) and, while such "off-label" use is permissible by the FDA, we lack adequate information about adverse consequences women may face when the drug is used for fertility treatments. Reported side effects of Lupron used for other conditions include rash, sensation of burning, tingling, itching, headache and migraine, dizziness, hives, hair loss, severe joint pain, difficulty breathing, chest pain, nausea, depression, emotional instability, loss of sex drive, dimness of vision, fainting, weakness, amnesia, hypertension, muscular pain, bone pain, nausea/vomiting, asthma, abdominal

²² Delvigne, A. & Rozenberg, S. (2002). Epidemiology and prevention of ovarian hyperstimulation syndrome: A review. *Human Reproduction Update*. 8(6), 559-577.

pain, insomnia, swelling of hands, general edema, chronic enlargement of the thyroid, liver function abnormality, vision abnormality, anxiety, and vertigo.

Use of Fertility Drugs and Risk of Cancer

Based on the conclusions of a sampling of studies and literature reviews investigating the relationship of fertility drugs and reproductive cancers in women, a strong link between the two has not been shown. However, even though most findings report little or inconclusive evidence of this link, nearly all of the study authors note that more research and continued monitoring of patients who have previously received or are currently undergoing treatment for infertility are warranted and necessary to determine long term risks. While most studies seem "reassuring" in their findings, conflicting study results are also mentioned. One particular study does find a small increase in uterine cancer after the use of clomiphene citrate, but concludes that more research is needed to validate these findings.²³

Researchers also note that there may be underlying factors that put certain groups of women at higher risk, but that more work needs to be done to determine these factors. It is also noted that approval for clinical use of clomiphene citrate was given in 1967; this would mean that many of the women who have taken this drug have only recently reached the point when hormonally related cancers would be diagnosed.

While most of the study authors seem confident in their findings, there is mention of various shortcomings of the studies, including small numbers of subjects, short follow-up time, and imprecise drug information. This also supports the need for continued studies.

Some doctors in Europe are turning toward "natural cycling" or "minimal" stimulation to reduce the chance of adverse health reactions. Natural cycling is done with no drugs, and only one egg is retrieved per cycle. Minimal stimulation involves injection of a lower dose of hormonal drugs, producing fewer eggs but exposing the woman to a lower amount of the drugs.

Risks from multiples gestation pregnancies

Women taking fertility drugs to stimulate the ovaries for IVF or in conjunction with AI have a higher rate of multiple births, and therefore face risks associated with multiple gestations. The risks are not unique to pregnancy with multiples, but occur at higher rates than ART pregnancies with singletons. Examples include Caesarean sections, gestational diabetes, high blood pressure, pre-eclampsia, anemia, and postpartum hemorrhaging. Some women choose to undergo "selective reduction," in which one or more fetuses are aborted, depending on the number she is carrying.

On an international level, regulation can play a role in the incidence of multiple gestations in IVF. Germany and Italy, for example, do not allow the destruction of embryos, and thus all embryos created in the IVF process must be implanted in the woman intending to become pregnant. In Europe, some countries are incorporating elective single embryo transfer (eSET) into their practice, and studies have found that this method can be used in good-prognosis

²³ Althius, MD, et al. (2005). Uterine cancer after use of clomiphene citrate to induce ovulation. *American Journal of Epidemiology*, 161(7), 607-615.

patients without compromising the rate of pregnancy.²⁴ eSET is usually performed in Europe in patients under age 40, as they have a better chance of success. Transferring one embryo virtually eliminates the likelihood of multiple pregnancies (unless the embryo divides on its own) and associated risks for both pregnant women and newborns.

IMPACT ON CHILDREN BORN THROUGH ART

The majority of studies on children born through ART have focused on IVF, which can impact infant health in the forms of low birth weight, premature birth, higher rates of caesarean deliveries, infant death, and congenital disabilities. Many of these are due to the high incidence of multiple gestations that are common when using IVF. In 2004, 50% of all IVF pregnancies in the US resulted in multiple births. That same year, 1% of all US births were from IVF, yet they accounted for 18% of all multiple births in the country.²⁵ The pressure to produce a child for the patient, accompanied by the high cost of treatment, contributes to these statistics, as the implantation of multiple embryos can increase the chance of a successful birth.

There have been conflicting studies on the increased risks of developmental delay and cerebral palsy. Chromosomal abnormalities have increased occurrence in children born through intracytoplasmic sperm injection (ICSI), but it is uncertain what the cause of this may be. Several recent studies also found "an unexpectedly high incidence of Beckwith-Wiedemann Syndrome²⁶ in children conceived with IVF."²⁷ Several studies have found that IVF children could have a 25-60% higher incidence of congenital disabilities and illnesses (compared to 1-3% in the general population). Research in this area is difficult to evaluate, however, due to varying definitions of negative outcomes and determining what effect the underlying infertility of a parent has on the child. Because of methodology problems with most of the studies, no firm conclusions have been drawn from the available data.

The risk of cancer has been studied as well, and while there are a few studies, most have not found a link between IVF and cancer in children. One exception is a recent study of IVF children in the Netherlands, which found a much higher than expected occurrence of retinoblastoma (eye cancer).²⁸ This has caused concern for some researchers, and they suggest further study on the issue.²⁹

http://www.cdc.gov/MMWR/preview/mmwrhtml/ss5606a1.htm

 ²⁴ Criniti, A, et al. (2005, December). Elective single blastocyst transfer reduces twin rates without compromising pregnancy rates. *Fertility and Sterility*, 84(6), 1613-1619.
 ²⁵ Wright, VC, Chang, J, Jeng, G, Chen, M, Macaluso, M. Assisted reproductive technology surveillance—United

²⁵ Wright, VC, Chang, J, Jeng, G, Chen, M, Macaluso, M. Assisted reproductive technology surveillance—United States, 2004. (2007, June 8) *MMWR* 56(SS06), 1-22. Available from the Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion at

²⁶ Beckwith-Wiedemann syndrome is a rare congenital growth disorder that causes large body size, large organs, and other problems.

²⁷ Gosden, R., et al. (2003, June) "Rare congenital disorders, imprinted genes, and assisted reproductive technology." *Lancet*, 361, 9373.

²⁸ Gosden, R., et al (2003, June).

²⁹ Gosden, R., et al (2003); De Rycke, M, Liebaers, I, and Van Steirteghem, A. (2002, October). Epigenetic risks related to assisted reproductive technologies. *Human Reproduction*, 17(10) 2487-2494; Schieve, Laura, et al. (2004, June). Are children born after assisted reproductive technology at increased risk for adverse health outcomes? *Obstetrics & Gynecology*, 103(6), 1154-1163.

PGD has not yet shown to lead to problems for children born after using this procedure. At the same time, researchers say it will take several more decades before long-term outcomes can be determined, since the oldest children born after PGD are now only 17 years old.

Many researchers have stated that more study of these issues is warranted; a central concern is the difficulty in distinguishing if the infertility or the treatment is the cause of negative impacts on children conceived through IVF. Researchers have also asserted that the studies should be evaluated in a way that takes into consideration potential methodological limitations. One team of researchers suggests that future studies begin pre-conception and follow subjects through delivery to evaluate child health status.³⁰

For children born using donor sperm or eggs, an issue that is receiving increasing attention is the emotional impact of donor anonymity, in which children do not know the identity of their biological mother or father. The issues are not dissimilar to those faced by children who are adopted. According to Laura Shanner, professor at the University of Alberta in Canada, "…infertility counselors and donor offspring themselves document common experiences of grief, loss, isolation, disconnection, struggles with identity formation, and anger at secrets being kept about them." ³¹ In Canada, debate is currently taking place about whether to end current system of donor anonymity. In 2005, the UK changed their anonymity law to require that sperm and egg donors agree to reveal their identity when their offspring reach age 18.

CONTEXT OF ART USE

Knowledge of the array of technologies currently in use, reasons for use, and their health impacts on women and children is an important starting place for understanding ART. The technologies do not, however, exist within a vacuum, but in a world dominated by economic, political, and social inequities. Because the technologies are for sale, ART also functions within a highly commercialized environment. As is common with most public health issues, the commercial environment surrounding ART can put profit over health. Political divisions and tensions have also created an environment of minimal and uneven regulation. Understanding the industry and regulatory context in which ART is used is a critical component of analyzing its implications and for beginning to develop socially just policy proposals.

THE ART INDUSTRY

The field of ART is a multi-billion dollar industry, estimated from \$3-5 billion a year in the United States. Debora Spar writes in <u>The Baby Business</u>,³² "In 2004, more than one million Americans underwent some form of fertility treatment, participating in what had become a nearly \$3 billion industry." These treatments included IVF, fertility drugs, diagnostic tests, donor eggs, surrogate carriers, and donor sperm.

³⁰ Schieve, L, et al (2004).

³¹ Retrieved from http://www.law.ualberta.ca/centres/hli/pdfs/hlr/v11_3/06shannerfrm.pdf

³² See Spar's book for an excellent analysis of ART as a "baby business:" 2006, Harvard Business School Publishing Corporation.

Fertility clinics and specialists, egg brokers, and sperm banks sell their services to enable people to have genetically-related babies. On one end, women and men wanting to have a child are consumers; on the other end, women and men participate in the service process as egg donors, sperm donors, and surrogates. In response to those who object to the characterization of ART as an industry, Debora Spar asserts "This market…remains largely unacknowledged. No one likes to admit to manufacturing babies or to earning profits in the process. No one wants to argue that the baby business *should* be seen as commerce, or that its practitioners should be held to some kind of regulatory standard." Spar asserts that "…the market for fertility treatments is vibrant, competitive, and expanding in the absence of any kind of formal controls." The rapidly-expanding number of fertility clinics, egg brokers, sperm banks, and surrogacy services is a testament to the ever-growing ART market.

Fertility Clinics

Fertility clinics market their services through all major media forms, including web, newspaper, public transportation ads, and radio. An industry catering to fertility clinics' marketing needs has emerged, providing publicity specifically for the fertility industry. Internet Health Resources (ihr.com) has two parts to its business: one for consumers (Web site listings for products, clinics, services), and one for professionals (Web site development and promotion).

Market for Eggs

Spar estimates the trade in human eggs at \$38 million a year. Egg donors are recruited in three ways: through fertility clinics directly (egg donor program as part of clinic), "egg brokers" (recruit women to sell eggs to fertility clinics), and individuals (post in newspapers, online, etc.). There are over 100 egg donation agencies in the US. *Craigslist*, the world's biggest classified ad website, has an average of 50 ads looking for egg donors every day.

An estimated 75% of egg donors in the US are college students. Women on college campuses are a prime target for egg donation advertising because they are likely to be young, healthy, and in need of money. Young women generally produce a greater number of healthier eggs from hormonal stimulation, and those in college are perceived to be able to follow the extremely regimented process of daily injections required for multiple egg retrieval. Because of class bias, there is an expectation that they have greater intelligence than women not in higher education, with the accompanying assumption that intelligence is hereditary. There is also an expectation that they will have other "desirable" characteristics such as artistic, athletic, and/or mathematic ability.

ASRM's Ethics Committee advises that payment over \$5,000 for one cycle of eggs requires justification and payment of more than \$10,000 is not appropriate. Ads for more than \$10,000, however, routinely appear in private ads requesting specific characteristics, such as attendance at an Ivy-league university, high SAT scores, and specific height, eye color, and hair color. Some ads offer as much as \$80,000 (UC Berkeley campus newspaper, 2006) or \$100,000 (UCSF campus newspaper, 2006).

Market for Sperm

In 1980 there were 17 frozen sperm banks in the country; by 1999, there were more than 100. Sperm banks usually charge about \$200-500 per specimen. Donors themselves are paid about

\$75 each time they provide a viable specimen. At the Sperm Bank of California, donors must make a one year commitment and donate sperm at least once a week. They must be at least 5'7", have no chronic health problems, and provide medical information about both sides of their genetic family. They are paid \$75 for every ejaculate that meets the minimum sperm count, and this payment increases to \$90 after their first 25 acceptable ejaculates. After they complete the exit blood test, they are paid an additional \$200.

Market for Wombs

There is a patchwork of laws on surrogacy agreements in individual states. All surrogacy contracts are explicitly prohibited by law in Washington, DC and in five states (AZ, MI, IN, NE, NY). Three states (KY, LA, ND) prohibit genetic surrogacy but do not address gestational surrogacy. In the rest of the states, it is either legally permitted, not addressed in law but addressed in court cases, unclear, or not addressed in law at all. There is no law on a federal level. Given the high cost of hiring surrogates in the US, an international market has emerged. There has been a recent trend in "outsourcing" for surrogates, in which US couples or individuals contract with a woman overseas who is paid to carry their child.

Reproductive Tourism

Going to other countries for ART due to lower cost or less restrictive laws has given rise to an international market known as "reproductive tourism." India, for example, does not have guidelines that address foreigners hiring Indian surrogates. China and Thailand are also countries where individuals or couples, often from countries that ban surrogacy or have strict regulation, are hiring surrogates.

People from other countries where payment for eggs is banned come to the US because it is not regulated and it is easy (if you have money) to buy eggs here. In the UK, there is a shortage of eggs and in 2005, newspapers reported on a Romanian clinic that had recruited poor women to "donate" their eggs for the equivalent of one to two month's salary to UK couples.

REGULATION OF ART

Despite it being a \$3-5 billion industry with significant ethical challenges and critical issues related to the health and well-being of women and children, the ART industry is almost entirely unregulated in the US. In the public sphere, ART is discussed in the context of abortion politics, and policy development is paralyzed by ethical debates about the moral status of the embryo.

One of the only federal regulations in place regarding ART is the Fertility Clinic Success Rate and Certification Act of 1992, which requires that fertility clinics report their success rates annually to the Society for Assisted Reproductive Technology (SART) for publication on the website of the Centers for Disease Control and Prevention (CDC). There is no penalty for failing to comply, aside from being listed as a "non-reporter" in the CDC's publication. There are professional organizations (SART and ASRM) that have requirements for membership, and the Federal Trade Commission has had some influence on clinics that have advertised inappropriately, but for the most part regulation of fertility clinics and the use of ART comes from a patchwork of state laws.³³

The commercial aspect of ART, linked with minimal regulation, creates an unstable environment for ART consumers, in which information, services, and policies are inconsistent, incomplete, and sometimes incorrect. In a recent study of all SART affiliated fertility clinics with websites, researchers found the information provided "did not routinely meet the AMA guidelines for websites delivering medical health information."³⁴ It was also determined that "the quality of hospital center websites is superior to that of private clinics" and that "websites affiliated with academic institutions are more extensive in content and frequently include links to health research and educational websites."³⁵ The lack of regulation of the industry and the accompanying gap in reporting on adverse health reactions is a major reason there has not been more research and data on the health impacts of ART.

International

While the United States has not produced much regulation in this area, many countries have enacted some form of regulation of ART. The only two countries with comprehensive regulation that cover the use of all sperm, eggs, and embryos, whether for fertility or research, and apply to public and private ventures, are the UK and Canada.

The UK's Human Fertilization and Embryology Authority (HFEA), established in 1990, oversees all fertility treatments and embryonic research in the UK. The HFEA is responsible for the licensing and monitoring of all clinics offering IVF, donor insemination, and the storage of eggs, sperm and embryos. The HFEA produces a Code of Practice, which gives guidelines to clinics about the proper conduct of licensed activities, and keeps a formal register of information about donors, treatments and children born from those treatments. The HFEA has been criticized for moving technological development forward quickly while using its presence as a regulatory body to assuage the public that enough oversight is in place.

Canadian legislation created the 2004 Assisted Human Reproduction Act (AHRA), which prohibits the use of certain ART, including sex selection (except to prevent, diagnose, or treat a sex-linked disorder or disease), commercial surrogacy, the sale of gametes and embryos, and germline engineering. The AHRA also established the Assisted Human Reproduction Agency of Canada (AHRAC) to develop and oversee regulations covering these and other permitted activities. Similar to the HFEA in the UK, the AHRAC is responsible for licensing and monitoring all private and public fertility clinics, research facilities and other institutions whose research or commercial activity involves human gametes or embryos. Due to the integral role feminist groups in Canada played in drafting and supporting the law, the AHRA is prefaced with principles that express the importance of safeguarding the health of women and children, ensuring free and informed consent, and preventing discrimination and the commercial exploitation of reproduction.

 ³³ For a detailed description of ART regulation, including court cases, see Arons, J. (2007). *Future choices: Assisted reproductive technologies and the law.* Retreived from <u>http://americanprogress.org/issues/2007/12/pdf/arons_art.pdf</u>
 ³⁴ Jain, T & Barbieri, R. (2004). Website quality assessment: Mistaking apples for oranges. *Fertility and Sterility.* 83(3), 545-547 T.

³⁵ Jain & Barbieri (2004).

Some countries have limits on the number of embryos that may be implanted in a woman through IVF. The HFEA limits the number of embryos implanted to no more than two for all women under age 40, and no more than three for women over age 40. Other countries that limit the number of embryos include Brazil, Belgium, Denmark, Hungary, Saudi Arabia, Singapore, and Switzerland. Additionally, there are some countries that place restrictions on who may use these technologies and how. Italy, for example, restricts the use of IVF to heterosexual couples only, and does not allow the use of donor sperm or eggs. The number of embryos created is capped at three and all embryos created must be implanted. Germany also limits the number of embryos are illegal).

PGD policy has varying levels of restriction throughout the world. In the UK, approval to use this technology rests with the HFEA. The HFEA allows PGD for individuals who have a family history of "serious genetic disorders" and prohibits it for sex selection for "social or cultural reasons." Each individual or couple wanting to do PGD must make a request to the HFEA. In Canada, the AHRA prohibits PGD for sex selection except for preventing, diagnosing or treating sex-linked diseases. The agency created under the AHRA has not yet been established; this agency will have the means to set regulatory and licensing standards for PGD in accordance with the principles of the AHRA. PGD is illegal in Germany, Austria, and Switzerland. In France, India and the Netherlands, regulation has been enacted to determine for which purposes PGD may be used. In Japan, while there is no current law banning PGD, the Japanese Society of Obstetrics and Gynecology requires its members to request permission to perform this procedure.

The variation in national laws surrounding ART allows individuals, couples, and clinics to find the services they are looking for, whether in their own country or another. Outsourcing surrogacy to India and importing eggs from Romania illustrate the globalized nature characterizing the ART industry and the growth of reproductive tourism. The US is far behind other countries in ensuring adequate oversight of ART.

MOVING TOWARD SOCIALLY JUST POLICY

NEXT STEPS

If social justice organizations and movements in the US do not participate in the policy-making process regarding ART, the debate will continue to be dominated by the polarized voices of libertarians on one end and anti-choice conservatives on the other. Concerns related to the health and integrity of women, and of communities of color, disability communities, LGBTQI communities, and poor and low-income communities will be ignored or dismissed. Without these critical voices:

- ART will continue to be developed and used without sufficient research on the impact on women and children.
- Access to ART will continue to be limited to those who can afford it.
- Genetic screening technologies will continue to be used so parents can select the characteristics they want for their children, to select against disability, select for sex, and with an increasingly expanding list of traits to choose from.

• The organized anti-choice right wing religious conservative movement will continue to assert that ART should only be used by heterosexual married couples, and they will continue to co-opt women's rights language to support their agenda of "protecting" embryos.

CGS' Gender and Justice Program is committed to promoting a reproductive justice perspective on the development and use of ART and to work with our allies in multiple social justice movements to develop socially just policy recommendations that safeguard the health and dignity of all communities and individuals affected. The events G&J has been hosting bring social justice leaders together to discuss these complex issues, from the areas of reproductive health, rights and justice; racial justice; LGBTQI rights; disability rights; human rights; and environmental justice. We are currently working with our allies to launch a national multimovement coalition dedicated to developing a socially just policy agenda related to issues of new reproductive and genetic technologies.

In the last few years, the reproductive justice movement has begun to integrate issues related to ART and new genetic technologies into their national agenda. We hope that the reproductive health and rights movements will incorporate these important issues as well. We invite organizations involved in all three of these movements to participate in regional and national conversations taking place and to integrate ART issues and other new genetic and reproductive technologies into their organizational agendas. The goals and questions articulated at the beginning of this document offer a roadmap for capacity-building, coalition-building, and policy proposals for those interested in moving this work forward.

This document is a work in progress. We welcome both your feedback and your sharing of this memo with your allies. We are at a threshold in which we can affect the course of ART policy and practice in the US. Together we have the opportunity to ensure that reproductive justice principles are embedded in the foundation of this policy.

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