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Nanette R. Elster

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ART FOR THE MASSES? RACIAL AND ETHNIC INEQUALITY IN ASSISTED REPRODUCTIVE TECHNOLOGIES*

Nanette R. Elster, JD, MPH

INTRODUCTION

According to the National Center for Health Statistics about ten percent (10%) of the population of childbearing age suffer from infertility, which is defined as the inability to conceive after one year of unprotected intercourse. Overall, the prevalence of infertility in married couples is 7.1%; in Black married couples, 10.5%; and in Hispanic married couples, 7.0%.¹ Despite these figures, the seeking out of infertility services has been most common among non-Hispanic White women at a rate of 10.7%.² A number of factors may account for this difference including issues such as insurance coverage, socioeconomic status, cultural differences, effectiveness of treatment and general accessibility. This paper will discuss some of the barriers that may contribute to the current racial and ethnic disparities in the use of assisted reproductive technologies (ARTs) and provide recommendations for reducing these inequalities. The paper will begin with a discussion reproductive rights and whether ART fits within notions of procreative liberty. Next, it will discuss some of the historical antecedents of racial inequality in reproductive health care, followed by an overview of infertility and ART in the US. The paper will then review issues of race and infertility services and some of the barriers to care. Finally, the paper will conclude with some recommendations on how to address those current barriers.

* This paper was presented at the DePaul sponsored symposium: "From Selma to Washington: Disentangling Fact From Fiction: The Realities of Unequal Health Treatment," March 5, 2005.

¹ CENTERS FOR DISEASE CONTROL AND PREVENTION/NATIONAL CENTER FOR HEALTH STATISTICS, SERIES 23, NO. 19, FERTILITY, FAMILY PLANNING, AND WOMEN'S HEALTH: NEW DATA FROM THE 1995 NATIONAL SURVEY OF FAMILY GROWTH, (1997).

² See, e.g., Women's Health USA 2005: Health Status Special Populations, http://www.mchb.hrsa.gov/whusa_05/pages/0430is.htm.

BACKGROUND

In the United States, there is a “recognized protection accorded to liberty relating to intimate relationships, the family, and decisions about whether to bear and beget a child.”³ The use of ART to bear or beget a child is an issue steeped in controversy. If such a right does exist, it would likely be considered a negative right – meaning a right which one should be free to exercise without government interference.

One court does seem to suggest that such a right might exist. In the 1990 7th Circuit Court of Appeals decision *Lifchez v. Hartigan*, the court held that “It takes no great leap of logic to see that within the cluster of constitutionally protected choices that includes the right to have access to contraceptives, there must be included within that cluster the right to submit to a medical procedure that may bring about, rather than prevent, pregnancy. . . .”⁴ The court in that case was reviewing an Illinois law that made it a crime to perform embryo or fetal research. The law did allow in vitro fertilization, but would not permit such things as embryo donation, embryo cryopreservation or preimplantation genetic diagnosis.

Putting the rights argument aside, however, one might consider the use of ART to be a matter of social justice. Bioethicist and legal scholar Dorothy Roberts asserts that “[The] dominant view of liberty reserves most of its protection only for the most privileged members of society Reproductive freedom is a matter of social justice . . . [P]rocreation's special status stems as much from its role in social structure and political relations as from its meaning to individuals.”⁵

Because ARTs provide an individual solution to what might be perceived as a public health problem, some critics argue that “such resource allocation in effect devalues the structural and societal causes of fertility/infertility.”⁶ It is argued that “By emphasizing expensive and often unsuccessful reproductive technologies, the priorities of the medical and scientific community de-emphasize other basic societal

³ *Planned Parenthood v. Casey*, 505 U.S. 833, 857 (1992).

⁴ *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1377 (N.D. Ill. 1990), *aff'd without opinion sub nom. Scholberg v. Lifchez*, 914 F.2d 260 (7th Cir. 1990).

⁵ See DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION AND THE MEANING OF LIBERTY* 7, 294, 312 (1997).

⁶ LAURIE NSIAH-JEFFERSON & ELAINE J. HALL, *Reproductive Technology: Perspectives and Implications for Low-Income Women and Women of Color*, in *HEALING TECHNOLOGY: FEMINIST PERSPECTIVES* 108 (Kathryn Strother Ratcliff et al. eds., 1989), *available at*

<http://www.hsph.harvard.edu/grhf/WoC/reproductive/nsiah.htm>.

medical problems that have a more substantial impact on women's ability to bear healthy children."⁷

HISTORICAL ANTECEDENTS OF RACIAL INEQUALITY IN REPRODUCTIVE SERVICES

Racial inequality in reproductive services has existed long before the advent of ARTs and may, according to some, be perpetuated by the increasing use and access to ARTs by some groups and not by others. In fact, one commentator, in considering the history of social control over the reproduction of African-Americans argues that "excluding infertility services from HMO contracts may be the latest means of ridding society of certain minority groups."⁸ Another critical commentator says "[a]lthough the new reproductive technologies cannot be construed as inherently affirmative or violative of women's reproductive rights, the anchoring of technologies to the profit schemes of their producers and distributors results in a commodification of motherhood that complicates and deepens power relationships based on class and race."⁹ She views ARTs not so much as a form of eugenics, but more as an aggravating factor in an existing inequality of power.¹⁰

The social controls that have historically been imposed on reproductive rights have continually had a disproportionate impact on or the potential to disproportionately impact minorities. Justice Douglas, in the Supreme Court decision in *Skinner v. Oklahoma* addressing Government policy regarding compulsory sterilization, recognized the right to reproduce as "basic to the perpetuation of a race."¹¹ He wrote that the power to sterilize "[i]n evil or reckless hands . . . can cause races or types which are inimical to the dominant group to wither and disappear."¹² In fact, African-American and Hispanic women were those most likely to be sterilized.¹³ From forced

⁷ *Id.*

⁸ See Lisa M. Kerr, *Can Money Buy Happiness? An Examination of the Coverage of Infertility Services Under HMO Contracts*, 49 CASE W. RES. L. REV. 599, 627 (1999).

⁹ ANGELA Y. DAVIS, *Outcast Mothers and Surrogates: Racism and Reproductive Health in the Nineties*, in FEMINIST THOUGHT AT CENTURY'S END: A READER 355, 365 (Linda S. Kauffman ed., 1993), available at <http://www.hsph.harvard.edu/Organizations/healthnet/WoC/reproductive/davis.html>.

¹⁰ *See id.*

¹¹ *Skinner v. Oklahoma*, 316 US 535, 536 (1942).

¹² *Id.* at 541.

¹³ See Melissa Fraser, *Gender Inequality in In Vitro Fertilization: Controlling Women's Reproductive Autonomy*, 2 N.Y. CITY L. REV. 183, 202 (1998).

sterilizations or sterilizations without adequate consent¹⁴ to the restrictions on abortion access imposed by the Hyde Amendment which was first passed by Congress in the 1970's, prohibiting the use of federal Medicaid funds for abortions except in the event of rape, incest and endangerment of life;¹⁵ race has been a factor in the widening racial divide with respect to reproductive rights.

Against this historical backdrop, it is not surprising that racial inequalities are evident with respect to infertility services. The extent of the inequalities is unclear as little empirical research has been done; however one recent study was published in *Fertility and Sterility* addressing disparities in access to infertility services. This study examined at a state with mandated insurance coverage for fertility services and concluded that "[f]urther studies to better understand such disparities will be the next step toward providing equal and high-quality infertility treatment to all Americans."¹⁶ The remainder of this paper examines some of the potential barriers to infertility treatment among minority populations and suggests ways in which those barriers might be addressed to equalize availability of and access to reproductive services.

AN OVERVIEW OF INFERTILITY & ART IN THE US

Infertility is defined as the inability to conceive after 1 year of unprotected intercourse.¹⁷ Approximately 6.1 million women have impaired fertility.¹⁸ Leading factors contributing to female infertility include: Ovulation Disorder, Blocked Fallopian Tubes, Pelvic Inflammatory Disease (including sexually transmitted infections), Endometriosis, and Congenital Anomalies.¹⁹ As of 2002, the most recent year for which comprehensive data has been collected, over 400

¹⁴ See Angela Hooton, *A Broader Vision of the Reproductive Rights Movement: Fusing Mainstream and Latina Feminism*, 13 AM. U. J. GENDER SOC. POL'Y & L. 59, 70 (2005) (for a discussion of forced sterilizations in the Latina community).

¹⁵ CONSOLIDATED APPROPRIATIONS ACT OF 2004, Pub. L. No. 108-199, 118 Stat. 3 (2004).

¹⁶ Tarun Jain & Mark Hornstein, *Disparities in Access to Infertility Services in a State with Mandated Insurance Coverage*, 84 FERTILITY AND STERILITY 221, 223 (2005).

¹⁷ See Resolve, *Frequently Asked Questions about Infertility*, available at <http://www.resolve.org/main/national/trying/whatis/faq.jsp?name=trying&tag=whatis> (last visited August 22, 2005).

¹⁸ American Society for Reproductive Medicine, *Frequently Asked Questions about Infertility*, available at <http://www.asrm.org/Patients/faqs.html> (last visited August 22, 2005).

¹⁹ *Id.*

ART clinics were operating in the US and, approximately 115,000 ART cycles were performed resulting in over 45,000 live births. The average cost of IVF in the United States is \$12,400,²⁰ which can be quite burdensome for the average person given that only about fourteen states have passed laws that either mandate insurers to cover or offer coverage for infertility diagnosis and treatment.²¹ “ART includes all fertility treatments in which both eggs and sperm are handled. In general, ART procedures involve surgically removing eggs from a woman’s ovaries, combining them with sperm in the laboratory, and returning them to the woman’s body or donating them to another woman.”²² Although artificial insemination and taking of fertility drugs are treatments for fertility, they are not considered an ART for purposes of reporting and collecting success rates.²³

Much of the information about infertility usage and success is collected annually by the Centers for Disease Control (CDC) in conjunction with the Society for Assisted Reproduction (SART) pursuant to the federal mandate in the Fertility Clinic Success Rate and Certification Act of 1992.²⁴ The Act requires that fertility clinics report pregnancy success rates for each ART procedure performed to the Secretary of Health and Human Services through the CDC.

A wide range of information is required to be reported about both the Clinic and the Patients. Information about the Clinic includes whether the clinic is a member of the SART, whether services provided include surrogacy, and the total number of ART cycles performed during a year. Information about Patients includes demographic details, the patient’s history, medical reasons for the ART, source of oocyte, any ART complications, and information about the outcome of the procedure. Notably missing from this data collected, however, is information about the race and ethnicity of patients, educational level of patients, and the source of payment for such services. All this leads to the question: Who are the infertile?

²⁰ American Society for Reproductive Medicine, *Frequently Asked Questions about Infertility*, <http://www.asrm.org/Patients/faqs.html> (last visited August 22, 2005).

²¹ National Conference of State Legislatures, *50 State Summary of Laws Related to Insurance Coverage for Infertility Therapy*, <http://www.ncsl.org/programs/health/50infert.htm>.

²² Centers for Disease Control and Prevention, *Assisted Reproductive Technology: Home*, <http://www.cdc.gov/ART/index.htm> (last visited Nov. 3, 2005).

²³ *See id.*

²⁴ 42 U.S.C. § 263a-1 (2001).

INFERTILITY AND RACE

If one reads the newspaper, picks up a magazine or flips on the nightly news, or any talk show, for that matter, the infertile look to be white, middle to upper middle class couples or women, with relatively high levels of education.²⁵ While this may be an accurate depiction of those accessing infertility services, it is not necessarily an accurate reflection of those who are actually experiencing infertility. National data indicates that 6.4% of white women are infertile as compared to 7% of Hispanic women, 10.5% of black women and 13.6% of other racial groups.²⁶ Additionally, 8.5% of married women without a high school education or its equivalent are infertile as compared to 5.6% of married women with a bachelor's degree or higher.²⁷ Some experts believe that due to underreporting, the prevalence of infertility among minorities may be even higher.²⁸

Race and the Use of Infertility Services

The most recent comprehensive collection of data regarding use of infertility services broken down by race is from 1995 and was published in 2000.²⁹ This study indicates that of the nearly 11,000 women surveyed in 2000, of those using infertility services, 11.1% were Hispanic, 13.6% were Non-Hispanic Black and 70.6% were Non-Hispanic White.³⁰ It is unclear whether this figure reflects a choice based on cultural preferences of the patient as some cultures are reticent to seek fertility services or whether the race or ethnicity of the physician may influence his or her treatment recommendation. However, the survey did indicate that when seeking services regarding

²⁵ See Lisa M. Kerr, *Can Money Buy Happiness? An Examination of the Coverage of Infertility Services Under HMO Contracts*, 49 CASE W. RES. L. REV. 599, 605 (1999).

²⁶ U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, FERTILITY, FAMILY PLANNING, AND WOMEN'S HEALTH: NEW DATA FROM THE 1995 NATIONAL SURVEY OF FAMILY GROWTH 61 (1997).

²⁷ *Id.*

²⁸ See Dorothy Roberts, *Race and the New Reproduction*, 47 HASTINGS L.J. 935, 941 (1996) ("Blacks may find it more emotionally difficult to discuss their problem with a physician . . ."). See also Laurie Nsiah-Jefferson & Elaine J. Hall, *Reproductive Technology: Perspectives and Implications for Low Income Women and Women of Color*, in HEALING TECHNOLOGY: FEMINIST PERSPECTIVES 83-118 (Kathryn Strother Ratcliff et al. eds., 1989), available at <http://www.hsph.harvard.edu/grhf/WoC/reproductive/nsiah.html>.

²⁹ See generally Elizabeth Hervey Stephen & Anjani Chandra, *Use of Infertility Services in the United States: 1995*, 32 FAMILY PLANNING PERSPECTIVES 132 (2000).

³⁰ *Id.*

prevention of miscarriage, white women were twice as likely to receive ovulation drugs as compared to their black and Hispanic counterparts. In fact, according to the Families of Color Initiative of the Ferre Institute, “[o]f women facing infertility, 44% will seek some intervention; however, among African American women only 31% will seek treatment for this problem.”³¹

Race and Treatment Outcomes

To date, the empirical research examining differences in the outcome of fertility treatment based on race has been minimal. In part, this may be a result of the limited use of these high tech treatments by minorities. In the handful of studies that have been published, however, the success of fertility treatment for minority women seems to be lower than that for white women. One study, published in June of 2000 found that black women are 2.6 times less likely to become pregnant through IVF as compared to white women.³² The authors speculate that the lower pregnancy rate may, in part, be due to the fact that the black patients in the study had suffered a longer period of infertility than their white counterparts and that they had a higher body mass index (BMI).³³ The authors concluded by urging further investigation into potential differences in treatment outcomes for other minorities in order to better tailor reproductive therapies to meet the needs of a wide range of patients.³⁴

More recently, an abstract was presented at the 2004 annual meeting of the American Society for Reproductive Medicine which found that overall, the live birth rate for whites and Hispanics was higher than that for blacks and Asians when controlling for age.³⁵ The authors concluded that race is an important demographic factor that may influence prognosis and potential treatment options

³¹ *The Hidden Problem of Infertility in the African American Community*, at <http://www.ferre.org/foci/hidden.html>. See also Roberts, *supra* note 26, at 941 (“Blacks may also harbor a well-founded distrust of technological interference with their bodies and genetic material at the hands of white physicians.”).

³² See generally Fady I. Sharara & Howard D. McClamrock, *Differences in In Vitro Fertilization (IVF) Outcome Between White and Black Women in an Inner-City, University-Based IVF Program*, 73 FERTILITY AND STERILITY 1170 (2000).

³³ *Id.*

³⁴ *Id.*

³⁵ See generally D. A. Grainger et al., *Racial Disparity in Clinical Outcomes from Women Using Advance Reproductive Technologies (ART): Analysis of 80,196 ART Cycles from the SART database 1999 and 2000*, 82 FERTILITY AND STERILITY S37 (2004).

BARRIERS TO INFERTILITY SERVICES

While it is clear that more research is necessary to begin to address those disparities which have a physiological basis, other factors may nonetheless contribute to the inequalities. One might argue that if ART was more accessible, more research may be done and the cause and subsequent resolution of those physiological barriers might occur, however, a lesser likelihood of success in treatment does not completely explain why minority populations are so underrepresented with respect to utilization of infertility services.

The barriers to infertility services are numerous and include physiological barriers as discussed previously; access, both physical and financial; cultural; and a lack of racially and ethnically diverse donors available to participate in collaborative reproductive arrangements.³⁶

Access

In the context of fertility services, access may take several forms and includes: financial access and physical access, i.e. where fertility centers are located. From the financial perspective, ART is well out of reach of many Americans as the cost of IVF is upwards of \$12,000.³⁷ Add a technique like preimplantation genetic diagnosis (PGD)³⁸ to the mix and the figure looms above \$15,000. Additionally, with insurance coverage limited at best, these technologies are only available those who can afford to pay out of pocket. For this reason, it is easy to see why access to infertility services is limited for some minority groups. “[S]eventy-five percent of low-income women in need of infertility services, a disproportionate number of whom are African-American, do

³⁶ Tarun Jain & Mark Hornstein, *Disparities in Access to Infertility Services in a State with Mandated Insurance Coverage*, 84 FERTILITY AND STERILITY 221, 223 (2005) (discussing collaborative reproductive arrangements). These arrangements include those situations in which donor gametes (egg or sperm) may be used to assist a couple or an individual overcome infertility and/or avoid passing on a genetic disease to offspring. This article details health disparities in a state mandating insurance coverage of fertility treatments theorized that barriers in accessing care “may include lack of appropriate information, racial discrimination, lack of referrals from primary care physicians, lack of adequate insurance coverage among lower socioeconomic groups, and cultural bias against infertility treatment.”

³⁷ REPRODUCTIVE MEDICINE, *supra* note 20.

³⁸ PGD is “[a] process in which early stage embryos created through in vitro fertilization are analyzed to detect certain genetic characteristics.” Glossary, Genetics and Public Policy Center, <http://www.dnapolicy.org/genetics/glossary.jhtml.html> (last visited Nov. 3, 2005).

not have access to those services.”³⁹ While coverage for infertility is not prohibited under Medicaid, one study found that 50% of the fertility centers surveyed refused patients who were on Medicaid.⁴⁰ And, for those without insurance, the situation is even bleaker, making this particularly burdensome among the Latina population in which more than 1/3 of woman are uninsured – the highest rate of uninsurance among racial groups.⁴¹

Racial disparity in access to reproductive services may be further exacerbated by the intersection of reproductive and genetic technologies. One example is that of PGD. PGD is “[a] process in which early stage embryos created through in vitro fertilization are analyzed to detect certain genetic characteristics.”⁴² PGD occurs at an earlier stage than prenatal diagnosis – before embryos are even transferred to the uterus which may be beneficial to those that need to terminate a pregnancy in the future.⁴³ PGD can be used for a number of reasons including to screen for disease, to select the sex of an embryo and/or to provide a genetically matched sibling.⁴⁴

This current limited accessibility to reproductive and genetic technologies forces us to consider the possibility of proliferation of another form of discrimination – genetic discrimination. A recently issued report from the Genetics and Public Policy Center stated that one concern among the public regarding the use of reproductive genetics is that “families who would face the greatest financial burden of caring for children born with conditions detectable via PGD may be the ones least able to afford it.”⁴⁵ This causes us to ask the question of whether

³⁹ Lisa M. Kerr, *Can Money Buy Happiness? An Examination of the Coverage of Infertility Services Under HMO Contracts*, 49 CASE W. RES. 599 (1999).

⁴⁰ See generally ROBERTS, *supra* note 5, at 253.

⁴¹ See generally Angela Hooton, *A Broader Vision of the Reproductive Rights Movement: Fusing Mainstream and Latina Feminism*, 13 AM. U. J. GENDER SOC. POL’Y & L. 59 (2005).

⁴² See Genetics and Public Policy Center, Glossary, <http://www.dnapolicy.org/genetics/glossary.jhtml.html> (last visited September 21, 2005).

⁴³ See generally Sozos J. Fasouliotis & Joseph G. Schenker, *Preimplantation Genetic Diagnosis Principles and Ethics*, 13 HUMAN REPRODUCTION 2238 (1998).

⁴⁴ See NATIONAL HUMAN GENOME RESEARCH INSTITUTE, *Reproductive Genetic Testing*, <http://www.genome.gov/10004766>. (providing an overview of some of the uses of PGD).

⁴⁵ See GENETICS & PUBLIC POLICY CENTER, *Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Options Related to the Genetic Testing of Human Embryos* (2004), http://www.dnapolicy.org/downloads/pdfs/policy_pgd.pdf.

such limited accessibility will widen the gap between the “haves” and the “have nots,” or whether we will begin to see the development of a genetic underclass.

These questions are not necessarily new and have previously arisen in the context of prenatal diagnostics. A study done in 1996 found that “[i]n addition to higher rates of infant mortality among minority populations, some research has indicated that the higher incidence of birth defects in black and Hispanic women may be linked to lower use of prenatal testing among these women.”⁴⁶ The reasons for this disparity were varied and include different cultural responses to disability, cultural sensitivity of health care providers, and socioeconomic considerations. As with other technological advances, financial barriers may be quite significant. For those without insurance or who rely on government funded programs like Medicaid (a disproportionate amount of women of color) the option of prenatal screening is oftentimes limited, thus the prospect of realistically gaining access to PGD seems remote at best.

Cultural

Financial barriers and income disparities are not the only obstacles to accessing fertility treatments including PGD. Cultural barriers exist as well. A number of factors contribute to the cultural barriers to infertility services including: social stigma and stereotyping, distrust of research/medical professionals, the lack of specialists from minority populations, and language barriers.⁴⁷

Research done by legal scholar Dorothy Roberts indicated that one black women seeking IVF said, “[b]eing African-American, I felt that we’re fruitful people and it was shameful to have this problem.”⁴⁸ This same sentiment was echoed and further articulated in an article in *Essence* magazine where the author discusses the discrete topic of infertility writing, “[i]n a culture that often portrays Black women as stoic earth mamas and baby-making welfare queens, this myth may be

⁴⁶ Miriam Kupperman et al., *Racial-ethnic Differences in Prenatal Diagnostic Test Use and Outcomes: Preferences, Socioeconomics, or Patient Knowledge?*, 87 *OBSTETRICS & GYNECOLOGY* 675 (1996).

⁴⁷ See Families of Color Initiative, *The Hidden Problem of Infertility in the African American Community*, <http://www.ferre.org/foci/hidden.html> (discussing the need for public awareness of infertility and its treatments in the African American community). See also Angela Hooton, *A Broader Vision of the Reproductive Rights Movement: Fusing Mainstream and Latina Feminism*, 13 *AM. U. J. GENDER SOC. POL’Y & L.* 59 (2005).

⁴⁸ ROBERTS, *supra* note 5, at 259.

especially potent among African-Americans.”⁴⁹ Also, in an online health resource for women, one article about infertility of black women describes the public image of African-American women as being “as lush and fertile as the black soil of the Motherland.”⁵⁰ These quotes all imply a perception or even a stereotype, if you will, of the Black woman as fertility goddess not only in the eyes of the broader society but also within the particular racial and cultural group. Such a perception may influence not only the decision to seek treatment, but also the assessment of the need for treatment by clinicians.

Differences in language and culture between infertility service providers and patients may be yet another obstacle, notwithstanding the scarcity of specialists who are themselves minorities which may also contribute to selection bias on the part of clinicians. Consider genetic counselors, for example. Of the 2100 genetic counselors currently in the United States, 91% are Caucasian as compared to 98.3% over a decade ago.⁵¹ The same sort empirical information does not seem to be available with respect to reproductive endocrinologists; however, anecdotal information does suggest that there are few black fertility specialists.⁵²

The difference in racial or ethnic background between the clinician and the patient may be relevant in that “[w]hen the counselor and the client hold different class and racial/ethnic positions in society, the interaction is likely to exhibit difference in power and even attempts at social control.”⁵³ Cultural sensitivity is of particular importance in the reproductive context especially given the history of social control over the reproduction of low income and minority women. At an even more fundamental level are the linguistic barriers. “Differences in

⁴⁹ Ziba Kashef, *Miracle Babies: One in Ten Black Women will Face the Anguish of Being Unable to Conceive, but Today's Fertility Treatments are Improving the Odds*, ESSENCE, January 1, 1998.

⁵⁰ See Linda Villarosa, *Infertility and Black Women*, <http://healthquestmag.com/html/infertility.asp?PrtrQ=PRINT>.

⁵¹ NATIONAL SOCIETY OF GENETIC COUNSELORS, INC., *Professional Status Survey 2004*, http://www.nsgc.org/careers/2004_PSS_Final_pw.pdf.

⁵² See ROBERTS, *supra* note 5, at 259.

⁵³ LAURIE NSIAH-JEFFERSON & ELAINE J. HALL, *Reproductive Technology: Perspectives and Implications for Low-Income Women and Women of Color*, in *HEALING TECHNOLOGY: FEMINIST PERSPECTIVES* 102 (Kathryn Strother Ratcliff et al. eds., 1989), available at <http://www.hsph.harvard.edu/Organizations/healthnet/WoC/reproductive/nsiah.html>.

language and culture between the provider and the patient can hinder communication and affect the quality of care that patients receive.”⁵⁴

Intertwined with the obstacles of language and cultural differences between patients and providers, exists a more general distrust of technology and new medical interventions. This distrust has historical antecedents rooted in the abuses of the Tuskegee syphilis study, the misunderstanding surrounding sickle cell carrier testing in the 1970's that led to the firing or grounding of black pilots if they were carriers of the sickle cell trait and publications such as the *Bell Curve*, which suggested a genetic link between race and intelligence.⁵⁵

Lack of Donors

For many, ART involves not simply IVF, but necessitates the use of an egg or a sperm donor as well because both the male and female partner may be experiencing infertility or a genetic condition which they are seeking not to transmit to any offspring. For minority populations, finding available donors of the same race may be very difficult. The research on this topic is quite sparse. One study in 2003 examining the data from one sperm bank found that “the inventory of donors is mostly Caucasian (68%), with some Asian (17%), some with mixed race or “unique” racial designations (11%), and a handful of Black/African-American donors (4%).”⁵⁶ One legal commentator has suggested that critical race theorists view the limited access of minorities to ART in combination with the limited types of donors recruited as a way of intentionally encouraging racial disparity,⁵⁷ raising the question of “the motivations and intentions of having medical reproductive technology services available for a limited subsection of society.”⁵⁸

⁵⁴ Angela Hooton, *A Broader Vision of the Reproductive Rights Movement: Fusing Mainstream and Latina Feminism*, 13 AM. U. J. GENDER SOC. POL'Y & L. 59, 73 (2005).

⁵⁵ ROBERTS, *supra* note 5, at 260-61. See also Melinda B. Kaufmann, *Genetic Discrimination in the Workplace: An Overview of Existing Protections*, 30 LOY. U. CHI. L. J. 393, 402-404 (1999); RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1996).

⁵⁶ Martha Ertman, *What's Wrong with a Parenthood Market? A New and Improved Theory of Commodification*, 82 N.C. L. REV. 1, 27-28 (2003).

⁵⁷ Kari Karsjens, *Boutique Egg Donations: A New Form of Racism and Patriarchy*, 5 DEPAUL J. HEALTH CARE L. 57, 79 (2002) (“[I]inking the disparate number of minority donors and the overwhelming number and demand for white donors, critical race theorists view as suspicious the profitable practice of encouraging a racial hegemony by limited minorities access to the ART services, as well as limited the type of donors recruited to one race.”).

⁵⁸ *Id.* at 80.

Most information that is published regarding minority donors indicates a paucity of ethnic diversity in the “gamete market.”⁵⁹ However, the author of this paper spoke with an egg donor recruiter, albeit not in a national market, who indicated that the problem is not insufficiency in available gametes from ethnic minorities, but an insufficiency of African-American and Hispanic recipients to match with those donors.⁶⁰

This is yet another area, ripe for empirical research to explore such questions as: Are minority donor’s not recruited? Is there a cultural bias against involving a third party such as an egg donor or sperm donor in reproduction? Is there a concern of exploitation not only by potential donors but also recruiters? What is the demand for minority donors? The answers to these questions may help to improve the balance, at least with respect to collaborative reproduction.

RECOMMENDATIONS FOR REDUCING RACIAL INEQUALITY IN ART

The reasons for the racial inequality with respect to fertility services are numerous and inextricably intertwined. However, reconsidering the market-oriented model under which reproductive services are currently provided may help to equalize the benefits to be gained from ART. Recommendations for reducing current disparities in fertility services include increasing access, increasing awareness, rebuilding trust, and supporting more research and reporting.

Access can be increased in a number of ways. Currently very few states mandate coverage for infertility services,⁶¹ and very few insurers provide such coverage voluntarily, however, estimates indicate that to offer such coverage would only increase member premiums by about \$1 - \$3 per month.⁶² Increasing insurance coverage for infertility

⁵⁹ *Id.* at 78-79; THE INTERNATIONAL COUNCIL ON INFERTILITY INFORMATION DISSEMINATION, INC., *The Harsh Facts of Life for Black People Seeking Egg, Sperm Donors*, at <http://www.inciid.org/fertinews/harshfacts.html>.

⁶⁰ Interview with an egg donor recruiter (Mar. 2005).

⁶¹ See National Conference of State Legislators, *50 State Summary of Laws Related to Insurance Coverage for Infertility Therapy*, <http://www.ncsl.org/programs/health/50infert.htm><http://www.ncsl.org/programs/health/50infert.htm> (last visited September 23, 2005).

⁶² See National Conference of State Legislators, *Insurance Coverage for Infertility Therapy*, <http://www.ncsl.org/programs/health/infert.htm>.

services is one way to improve access. Additionally, encouraging providers to be more open to accepting Medicaid and states to provide coverage for such services is yet another way to expand the availability of ARTs. Also, having fertility centers located in more diverse neighborhoods is yet another way to increase access to ART.

Public awareness about what infertility is and who suffers from infertility is yet another way to help reduce the current disparities. This can be accomplished both publicly and privately. The media can begin to use broader strokes when portraying infertility rather than perpetuating the stereotype of the white, affluent, educated couple as those who are infertile. Infertility really is colorblind and this is a message that can be conveyed through the popular press. A benefit to this may be an increase in the number of minority donors available. If donation can be seen to be helping to perpetuate a particular race rather than something exploitative of the donor, more donors may be willing to participate in collaborative arrangements.

Additionally, fertility centers can market in ways that reach across racial lines. The Ferre Institute formed the Families of Color Initiative in 2001 to among other things “create and implement social marketing strategy for increased awareness of the infertility issues confronting women and families of African descent.”⁶³

Rebuilding trust may occur through more research and more reporting. With more research and reporting comes more transparency and accountability, which may help to foster a sense of trust and comfort. Trust will grow if ARTs do not seem to be yet another social control measure over the reproductive choices of minorities. Increasing access is one way to accomplish this goal illustrating the very circuitous nature of this dilemma.

CONCLUSION

“[O]ne of our greatest responsibilities is to consider the full implications of our new knowledge not only for relieving human suffering and distress but for the social and cultural

⁶³ The Ferre Institute, *The Hidden Problem of Infertility in the African American Community*, http://www.ferre.org/family_build/foci/hidden.html.

institutions that are as critical as DNA to supporting our individual and collective lives.”⁶⁴

This quote from Harold Shapiro, former chair of President Clinton’s National Bioethics Advisory Commission reflects the enormous social responsibility in integrating these new reproductive genetic technologies into the colorful fabric of our society. While many wonderful family building options have and will come from developments in ART and genetics, sensitivity to the potential harms and inequalities that may arise and protection against them so society as a whole can reap the benefits is imperative.

⁶⁴ Harold Shapiro, *Reflections on the Interface of Bioethics, Public Policy and Science*, 9 KENNEDY INSTITUTE OF ETHICS JOURNAL 209, 221 (1999).

