Title
Engineering For Perfection: The False Promises of Gene Editing in Assisted Reproduction

Authors
Mukherjee, Meghna
Shirinian, Nairi

Publication Date
2022-07-06

Othering
& Belonging
Institute

Engineering for Perfection

The False Promises of Gene Editing in Assisted Reproduction

Meghna Mukherjee and Nairi Shirinian

RESEARCH REPORT

BELONGING.BERKELEY.EDU

JULY 2022

The Othering & Belonging Institute at UC Berkeley, formerly the Haas Institute for a Fair and Inclusive Society, is a vibrant hub of researchers, community leaders, policy-makers, artists, and communicators that advances research, policy, and work related to marginalized communities. It engages in innovative narrative, communications, and cultural strategies that attempt to reframe the public discourse around marginality and inclusion and respond to issues that require immediate and long-term action.

About the Authors

Meghna Mukherjee is a PhD Candidate in the Department of Sociology at UC Berkeley. She studies how emerging fertility and genetic technologies reflect and reproduce social inequities. Meghna is particularly interested in understanding how medicalized spaces and interactions around technologies reinforce social hierarchies pertaining to race, class, gender, and disability.

Nairi Shirinian is a practicing attorney with Sullivan & Triggs, LLP and a graduate of Berkeley Law. At Berkeley Law, Nairi's research focused on bioethics and critical disability theory. Nairi is interested in the intersection of law and social norms, specifically in the contexts of fertility and disability.

Special Thanks

Osagie Obasogie
Marcy Darnovsky
Emily Galpern
Katie Hasson

Co-sponsor

Center for Genetics and Society

Copy Editor

Stacey Atkinson

Design & Layout

Christopher Abueg

Citation

Meghna Mukherjee and Nairi Shirinian, *Engineering for Perfection: The False Promises of Gene Editing in Assisted Reproduction* (Berkeley, CA: Othering & Belonging Institute, 2022), https://belonging.berkeley.edu/engineering-for-perfection

Contact

Othering & Belonging Institute at UC Berkeley
460 Stephens Hall
Berkeley, CA 94720-2330
Tel. 510-642-3326
belonging.berkeley.edu

Published July 2022.

This report was co-sponsored by the Center for Genetics and Society

Contents

Introduction

CRISPR AND OTHER METHODS of gene editing have captured the public imagination, spurring countless lectures, articles, and think pieces about how this technology can shape humanity. Many of these conversations are concerned primarily with the seemingly boundless "potential" of human gene editing to both treat diseases in existing patients and alter the genes of future children and generations. The ethical implications of using technology to permanently alter the human genome are evident and often mentioned. But many discussions downplay the serious societal and ethical implications of human gene editing when they fail to assess it within the context of existing assisted reproductive technologies (ARTs) and the fertility industry. This brief extends public and policy discussions that contextualize human gene editing as an ART with scientific limitations and grave and irreversible social and political consequences.

CRISPR (short for "clustered regularly spaced short palindromic repeats") is a genome editing technology that can be programmed to recognize and cut snippets of DNA.[1] CRISPR is often described as a "search and replace" tool, where specific genetic sequences can be targeted, cut out, and replaced by other DNA to create desired genetic outcomes. CRISPR can be used in humans on both embryos or germ cells (eggs and sperm), which harbor heritable genetic material, and somatic or body cells.[2] Genome editing can be used on somatic cells to treat conditions in existing people, such as sickle cell disease or cancer. In these cases, the changes to the DNA are permanent, but stay within the individual.[3] In contrast, editing the cells of an early embryo ("germline editing" or "heritable genome editing")—the focus of this brief—means that, if the altered embryo is used to start a pregnancy, those changes will be copied into every cell in the developing body of the future individual, including sperm or eggs. Any such changes made to an embryo will pass to future generations.[4] Somatic gene editing is promising for treating existing patients and is generally supported if it can be done safely, effectively, and accessibly. Germline editing, on the other hand, raises safety, ethical, and social concerns because it can have unknowable and nonconsensual impacts on future children and generations.

Does CRISPR fulfill a medical or social purpose that is currently unaddressed by existing ARTs?

Are the possible risks defensible when there are existing alternatives for most of CRISPR's proposed reproductive uses?

Why do the scientific and medical communities fail to fully consider the potential pitfalls of using germline editing as an ART?

Some—but not all—advocates of human germline editing make an ethical distinction between medical edits (therapeutic interventions) and aesthetic or trait-based edits (enhancements). They argue that using CRISPR on embryos would be ethical if used to

prevent disease, but not to edit for nontherapeutic purposes. Some advocates go even further, arguing that this technology not only *can* but *should* be used to permanently edit out disease genes in individuals so that they do not pass those traits to their offspring.[5] Based on the technology's claimed potential,[6] early investments are already being made into developing CRISPR.[7]

However, CRISPR/Cas9 as a tool and technique remains an imperfect technology with potentially severe unintended social consequences. Engineering the human germline would open the door to very narrow definitions of who is deemed healthy or desirable enough to exist. The same technology that could allow scientists and fertility doctors to edit *out* genes associated with health issues would also allow them to attempt to engineer *in* traits and enhancements related to problematic social ideals and privileges—whiteness, tallness, intellectual ability, aesthetic preferences, athleticism—revisiting a tormented global history around eugenics. Editing solely to prevent disease would also contribute to stigmatizing less privileged, less able-bodied "others." Given such crucial concerns, we must question how necessary CRISPR is when it comes to reproduction.[8] Does it fulfill a medical or social purpose that is currently unaddressed by existing ARTs? Are the possible risks defensible when there are existing alternatives for most of CRISPR's proposed reproductive uses? Why do the scientific and medical communities fail to

Kentucky State Baby Fair in 1940 where babies were assessed and ranked based on social and developmental markers reflecting eugenics values.

Key Terms

Germ cells (or gametes)
Sex cells (eggs and sperm) that are used to pass on genes from generation to generation. Mutations in germ cells are passed on to offspring.

Somatic cells
All cells of the body except germ cells. Mutations in somatic cells can affect the individual but are not passed on to offspring.

Genome
The entire set of genetic instructions found in a cell.

Genetic engineering (or genome editing)
The process of directly manipulating one or more genes to alter the genetic makeup of an organism.

Gene therapy
An experimental technique for treating disease by altering the patient's genetic material. Most often, gene therapy works by introducing a healthy copy of a defective gene into the patient's cells.

Heritable genome editing (or germline editing)
Making changes to the genetic material of eggs, sperm, or any cells that lead to their development, including the cells of early embryos, and establishing a pregnancy.

Sources: Key terms from "Talking Glossary of Genetic Terms," National Human Genome Research Institute, accessed 2021 at https://www.genome.gov/genetics-glossary; "Heritable Human Genome Editing," The Royal Society, National Academy of Sciences, National Academy of Medicine, and International Commission on the Clinical Use of Human Germline Genome Editing, accessed 2022 at https://www.ncbi.nlm.nih.gov/books/NBK561519/.

fully consider the potential pitfalls of using germline editing as an ART?

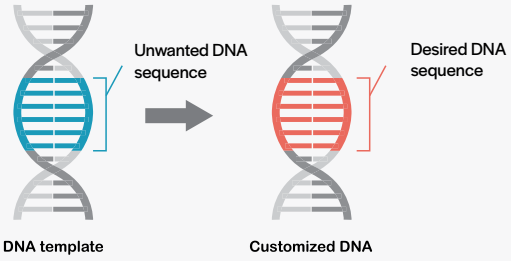
This brief argues that the implications of human germline editing should be understood in the context of ARTs and the for-profit fertility industry—one that reproduces and exacerbates the health and social disparities created by already existing reproductive technologies. There are important synergies that need to be considered. ARTs allow people to have children. Yet, germline editing would let them control *what kinds of children to have.* This entanglement suggests that the debate concerning the ethical implications of using CRISPR in reproduction must be situated within existing conversations regarding ARTs. Viewing CRISPR through this lens allows us to critique the goals of germline editing and to better understand how this new technology might not only exacerbate existing social and ethical dilemmas around ARTs, but also create entirely new challenges.

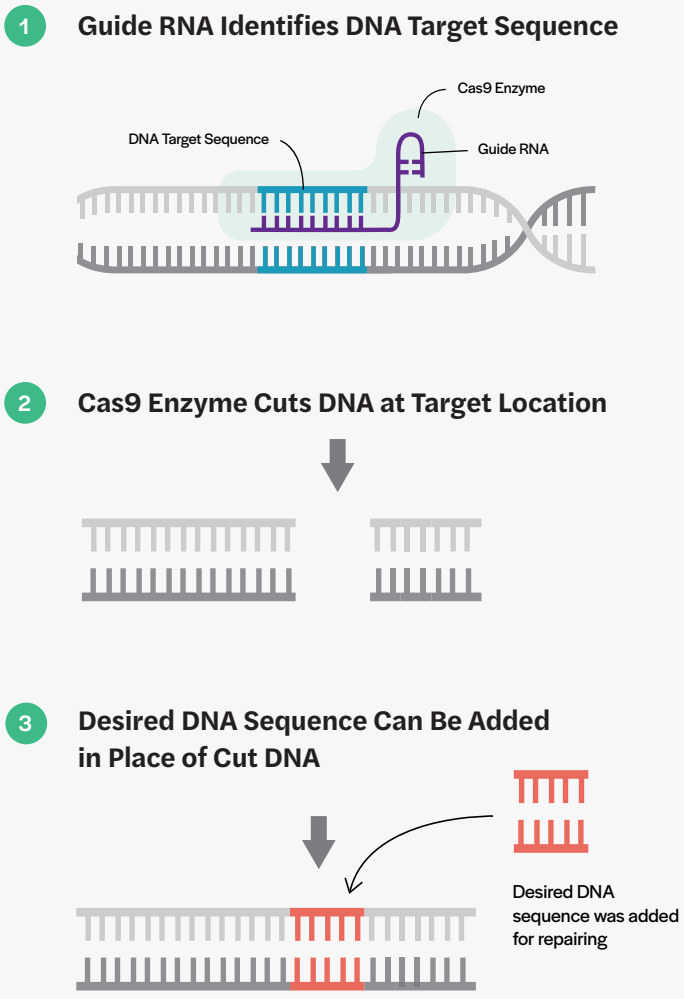
FIGURE 1

Summary of CRISPR technology

CRISPR is a gene editing technology that simplifies the process of modifying the genome of any organism. It exists among other biomedical innovations that allow for manipulation of genes and the genome through cutting and splicing of individual genes.

There are many uses of gene editing within agriculture, public health, and biotechnology. This brief does not comment on those uses; instead, it focuses solely on editing of the human germline—edits resulting in permanent and hereditable changes in human offspring.





ARTs and Reproductive Possibilities

PROPONENTS OF GERMLINE EDITING argue that CRISPR can be used to enable people who are at risk of passing on a genetic condition to have "healthy" genetically related children and to permanently edit out genetic conditions from both an individual and their hereditary line. Existing ARTs already address a wide range of reproductive goals beyond treating infertility, including enabling the birth of children without specific genetic conditions. Though these existing ARTs are not without health risks or ethical concerns, they render CRISPR redundant and unnecessarily dangerous when used on embryos.

Prenatal genetic carrier screening and counseling, preimplantation genetic testing (PGT), and egg and sperm donor selection all enable intended parents, who otherwise could not, to have genetically related children and/or to have children without passing on specific genetic conditions. Prospective parents can use prenatal genetic carrier screening and counseling to detect if they or their partner are carriers for particular genetic conditions and can determine the risk of passing on the condition. Prospective parents can then pursue fertility treatments such as in vitro fertilization (IVF) and PGT to select unaffected embryos for implantation, ensuring that certain genetic conditions are not passed down to their offspring. PGT, which includes screening and diagnosis, allows detection of a range of genetic conditions and chromosomal anomalies in developing embryos. Preimplantation genetic screening screens embryos to observe the number of chromosomes, and preimplantation genetic diagnosis also tests embryos for specific genetic diseases based on genetic parents' family histories.[9]

What Do Existing ARTs Accomplish?

- Enable prospective parents to have children
- Enable prospective parents to have genetically related children
- Enable prospective parents to have children without certain genetic conditions
- Do not alter embryo's DNA

These technologies allow prospective parents to select against embryos with particular genetic variants. In cases where these parents can use their own gametes when pursuing carrier screening and PGT, these technologies allow them to have children that are genetically related to them and lack a specific genetic condition that would have otherwise been passed down. Genetic relation within a family is important to many prospective parents, and many proponents of germline editing emphasize CRISPR's ability to help parents have children that are genetically related to them.[10] However, carrier screening and preimplantation genetic diagnosis already accomplish germline editing's goal of enabling parents to have children who are genetically related (unless third-party gametes have been used) and who lack certain genetic conditions—all without altering the embryo's DNA and the DNA of all its potential future generations.[11]

TABLE 1

Purposes and risks of ARTs

Technology	Purpose	Key Risks
In vitro fertilization	In vitro fertilization (IVF) is the joining of a woman's egg and a man's sperm in a laboratory dish, outside the body (in vitro). Fertilization refers to when sperm has attached to and entered the egg.	Risks include multiple births, premature delivery and low birth weight, ovarian hyperstimulation syndrome (see gamete donation risks), miscarriage, egg-retrieval procedure complications (see gamete donation risks), ectopic pregnancy, and stress.
Preimplantation genetic testing	Preimplantation genetic testing (PGT) is used to detect genetic changes in embryos that were created using IVF. To perform PGT, a small number of cells are taken from embryos and tested for certain genetic changes. The technique is often used to reduce the risk of having a child with a particular genetic or chromosomal condition.	The biopsy process, which removes cells from each embryo for PGT, has a small chance of damaging the embryo. Additionally, since the embryo(s) must be frozen while PGT is performed, they must also undergo a thawing procedure prior to transfer, which may damage embryos.
Gamete donation	Gamete donation entails a third-party individual providing their eggs or sperm (gametes) to an intended parent who seeks to pursue fertility care, or in some cases, to research institutions conducting gamete studies. The third-party individual providing gametes is often compensated.	The main risks associated with gamete donation pertain to egg provision. Ovarian hyperstimulation syndrome (OHSS) is a main risk: injectable fertility drugs, such as human chorionic gonadotropin, to induce ovulation can cause OHSS, in which the ovaries become swollen and painful. Severe forms of OHSS may be fatal. There may also be complications during the surgical egg retrieval. Use of an aspirating needle to collect eggs could possibly cause bleeding or infection or damage to the bowel, bladder, or a blood vessel. Risks are also associated with sedation and general anesthesia, if used.
Carrier screening	Carrier screening or testing is used to identify people who carry one copy of a gene variant that, when present in two copies, causes a genetic condition. This testing is offered to individuals who have a family history of a genetic condition.	Few physical risks are associated with carrier screening, as it can be conducted using blood or saliva sample. However, there may be emotional, social, or financial consequences of the test results. The possibility of genetic discrimination in employment or insurance is also a concern.

Sources:

"What Are the Uses of Genetic Testing?" National Library of Medicine, accessed 2022 at https://medlineplus.gov/genetics/understanding/testing/uses/.

"Assisted Reproductive Technology?" National Library of Medicine, accessed 2022 at https://medlineplus.gov/assistedreproductivetechnology.html.

"Gametes (Eggs and Sperm) and Embryo Donation," American Society for Reproductive Medicine, accessed 2022 at https://www.reproductivefacts.org/news-and-publications/patient-fact-sheets-and-booklets/documents/fact-sheets-and-info-booklets/gamete-eggs-and-sperm-and-embryo-donation/.

"In Vitro Fertilization (IVF)," Mayo Clinic, accessed 2022 at https://www.mayoclinic.org/tests-procedures/in-vitro-fertilization/.

"What Are the risks and Limitations of Genetic Testing?" National Library of Medicine, accessed 2022, https://medlineplus.gov/genetics/understanding/testing/riskslimitations/.

"Preimplantation Genetic Testing—FAQ," Washington University Physicians, accessed 2022 at https://fertility.wustl.edu/treatments-services/genetic-counseling/preimplantation-genetic-testing-faq.

Egg and sperm donor selection allows intended parents who cannot (or do not want to) use their own gametes to reproduce. Donor-assisted reproduction has been particularly important for single parents, LGBTQ couples, older women, and individuals who have undergone cancer treatments or injuries and can no longer use their own gametes. Donors are typically genetically screened and provide a detailed history of their family health background. Further, donor selection practices in the United States allow intended parents to view detailed profiles of their donors and in some cases meet donors. This enables intended parents to find donors who are similar to them in personality, aesthetics, sociocultural markers, and health background.

One of CRISPR's main claims is its ability to help parents create socially desirable families through carefully selecting and editing gametes and embryos in ways that "correct" health issues and select for other nonmedical preferences. However, egg and sperm donation, and the rigorous practices that go into screening and selecting donors, fulfill this purpose in a way that does not permanently reconfigure the human genome. In addition to stringent standards around donor screening and selection, fertility clinics often employ additional procedures before implanting embryos using donor gametes. For example, sperm washing to separate the sperm from semen fluid is a common procedure prior to IVF. It not only helps reduce adverse reactions during fertilization and implantation, but also removes the risk of transmitting diseases and infections such as HIV through semen.[12] Further, fertility clinicians and patients often utilize PGT procedures on donor-created embryos, as an additional layer of testing.[13]

The combination of prenatal genetic screening and counseling technologies for parents includes testing to understand genetic risks that a parent may pass on, counseling to learn of the various fertility treatments to avoid certain reproductive risks, and technology interventions (i.e., PGT) to achieve parents' specific reproductive goals. These technologies therefore preclude the need for CRISPR as a medical intervention at the embryo stage.

Unequal Access to Existing ARTs

ALTHOUGH SCIENCE AND MEDICINE have advanced significantly to care for populations' basic health needs, access to these resources remains unequally divided. Those from marginalized groups, such as people who are poor, homeless, Indigenous, refugees or immigrants, and racially marginalized, as well as individuals with physical and mental disabilities, continue to face obstacles when accessing health care.[14] In fertility care, cost-prohibitive treatments that allow people to reproduce and attempt to technologically control health outcomes are reserved largely for high earners.[15] Equal access to ARTs would not cure the ethical dilemmas they create because the *ways* these technologies are utilized are problematic. However, unequal access to ARTs exacerbates these ethical issues by prioritizing the reproduction of wealthy and able-bodied white women while being less attentive to—and often villainizing—the reproduction of those outside this category.[16] Understanding the current inequalities in access to fertility care forecasts how access to CRISPR will similarly be limited to white, nondisabled, and high-earning individuals.

The primary barriers to prospective parents accessing fertility treatment in the United States are cost, discrimination by providers, knowledge inequity, and distrust of the medical system due to past abuses of communities of color and poor people. These barriers disproportionately affect women of color, who face higher infertility rates but use ARTs at significantly lower rates than white women. As of 2012, approximately 6.4% of white women, 7% of Hispanic women, and 10.5% of Black women were infertile,[17] medically defined as unable to become pregnant after twelve months of regular intercourse.[18] Though women of color have higher rates of infertility, they are less likely to seek treatment and are more likely to wait longer before seeking treatment than white women.[19]

A Note on Abortion, ARTs, and Systemic Health Disparities

While we focus on access to ARTs in this brief, it is important to note that access to abortion is also patterned according to racial and socioeconomic disparities. Individuals from marginalized groups face multiple barriers to abortion, including lack of insurance access and waning public protections for access to abortions. When paired with lower access to ARTs, particularly carrier screening and preimplantation genetic testing, and exacerbated social and environmental harms in low-income communities, we increasingly see that restrictions and inequities around abortions are leading to genetic conditions becoming concentrated in marginalized communities.

For further discussion, see article by Khiara Bridges, "The Dysgenic State: Environmental Injustice and Disability-Selective Abortion Bans," *California Law Review* 110, No. 2, (April 2002).

Non-Hispanic white women are twice as likely as Latina women and four times as likely as Black women to use ARTs.[20] Many of the reasons women of color are likely to have higher incidences of infertility are also the same reasons these women lack equal access to fertility treatment as white women. Infertility rates correlate with education and socioeconomic status.[21] Infertility rates drop as education increases, and women who have lower socioeconomic status have higher rates of infertility due to poor environmental conditions, poverty, inadequate health care, poor nutrition, and other structurally determined lifestyle factors.[22] These social factors that contribute to infertility also serve to prevent marginalized women from accessing reproductive technologies.

Cost of fertility treatment is one of the most significant barriers to access for individuals from marginalized communities. ARTs are expensive and infrequently covered by insurance.[23] In the United States, only fifteen of fifty states require insurers to cover some form of infertility diagnosis and treatment, which means that individuals who cannot afford insurance often cannot access fertility treatments.[24] Further, each cycle of IVF costs between $12,000 and $17,000 (not including the cost of medication),[25] and most people will require more than one round of treatment.[26] As such, women with private insurance and women with incomes of more than 300% above the US poverty line are 50% more likely to have used ARTs.[27]

Consequently, existing fertility coverage policies across the country have the effect of a "de facto fertility policy" that discourages births among poor women of color and encourages births among working- and middle-class white women.[28] For example, there are no federal requirements for state Medicaid programs to cover fertility testing or treatments.[29] As such, low-income women on Medicaid often have mandatory contraceptive coverage and no coverage for fertility treatments, while women on private insurance are more likely to enjoy insurance benefits that will support fertility costs.[30] Even for many women on private insurance, fertility treatments are typically not covered, meaning that those accessing ARTs are doing so with their own resources.[31] Those who are single, nonheterosexual, or trans may also face disadvantages in insurance coverage for fertility care, as the medical definition of infertility is often inapplicable to and inappropriate for their needs.[32]

TABLE 2

Average cost of procedures associated with assisted reproduction in the United States

Procedure	Average Cost Before Insurance (US)
In vitro fertilization	$15,000–$20,000
Intrauterine insemination	$300–$1,000
Preimplantation genetic testing	$1,800–$6,000
Carrier screening	$100–$2,000
Gamete donation	$27,000–$47,000 (fresh donor eggs); $14,000–$20,000 (frozen donor eggs); sperm $300–$4,000

Sources:

"How Much Does IVF Cost?" Forbes Health, accessed 2022 at https://www.forbes.com/health/family/how-much-does-ivf-cost/.

"What Is IUI?" Planned Parenthood, accessed 2022 at https://www.plannedparenthood.org/learn/pregnancy/fertility-treatments/what-iui.

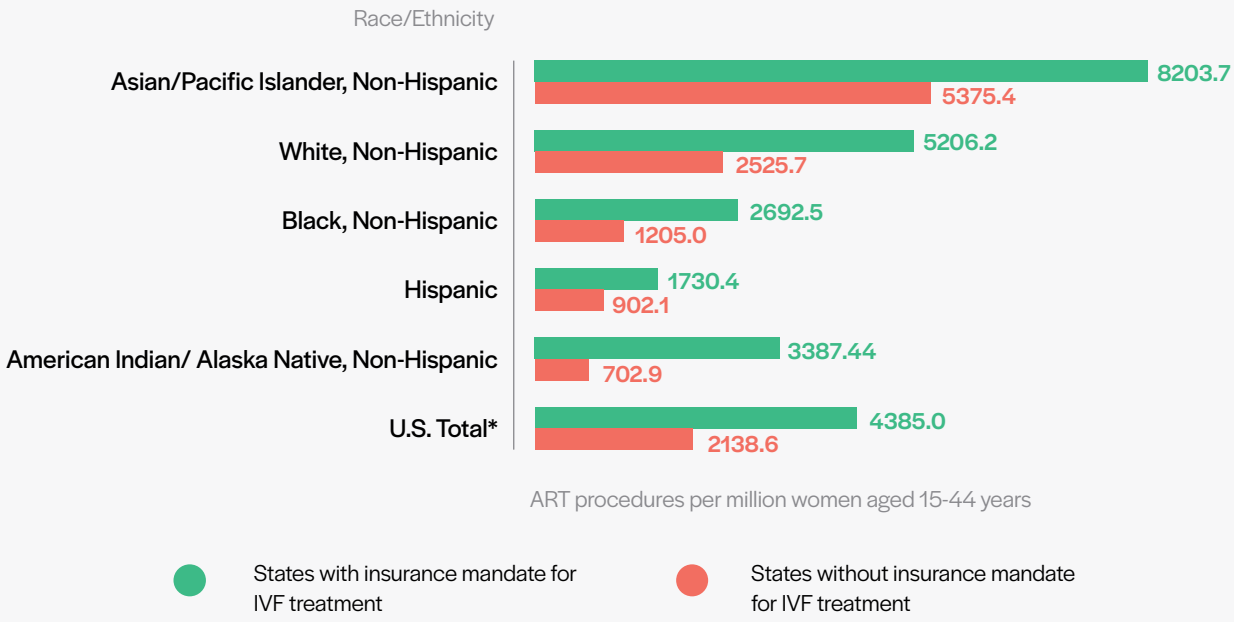
"What Is the Cost of Genetic Testing, and How Long Does It Take to Get the Results?" National Library of Medicine, accessed 2022 at https://medlineplus.gov/genetics/understanding/testing/costresults/.

"Donor Insemination," American Pregnancy Association, accessed 2022 at https://americanpregnancy.org/getting-pregnant/donor-insemination.

Cost is far from the only barrier to accessing ARTs. The persistent lack of regulatory oversight of ARTs has

FIGURE 2

ART utilization among each racial/ethnic category was higher in states with insurance coverage for ART in 2014, compared to states without insurance coverage for ART



ART procedures per million women 15-44 years of age by race/ethnicity and presence of insurance coverage mandate for IVF treatment in the United States, 2014. Two or more races not shown. US Census racial/ethnic categories for each state in 2014 among women 15-44 years of age were used to calculate the ART procedures per million women rate. US territories, banking, research, and oocyte thaw cycles, as well as non-US residents were excluded from the analysis. *US total of ART procedures after exclusions = 154, 876. ART, assisted reproductive technology; IVF, in vitro fertilization.

Source: A. C. Dieke et al., "Disparities in Assisted Reproductive Technology Utilization by Race and Ethnicity, United States, 2014: A Commentary," *Journal of Women's Health* 26, No. 6 (June 2017): 605-608.

Because the costs associated with CRISPR germline editing will be even higher than existing ARTs, users of gene editing technologies for reproductive purposes will likely also predominantly be of the same white and upper-middle-class demographic, further widening the gap between those who have access to ARTs and those who do not.

created a field that remains steeped in practitioners' arbitrary biases, inconsistent medical practices, and prejudices.[33] Discrimination by medical providers both results in denials of treatment for marginalized individuals and contributes to these communities refraining from seeking ART services in the first place.[34] Medical professionals wield tremendous power in evaluating who is worthy of having children. As such, marginalized women of color, low-income groups, or those with disabilities regularly experience barriers to receiving an infertility diagnosis or treatment.[35] ART professionals may use "common sense" to evaluate parenting ability among patients seeking

fertility treatments, often refusing treatment as a result of biases based on racial stereotypes, disability, sexual orientation, or marital status.[36] For example, it has been common practice for fertility doctors and genetic counselors to criticize women's choice to bring to term a child with known chromosomal or genetic disabilities.[37] In a survey conducted in 2005, one in five fertility treatment providers reported denying treatment for unmarried women, and one in two providers reported denying services for single men or same-sex couples.[38] Many ART providers also perceive women of color as "hyperfertile" and men of color as "hypersexual," making it especially difficult for people of color to seek fertility treatment.[39] Further, routine discrimination by providers and structural barriers to health care, such as lack of accommodations for patients with disabilities,[40] have resulted in mistrust among these communities toward medical providers, making marginalized individuals less likely to seek fertility treatment than their white and nondisabled counterparts.[41]

"Liberal eugenics"

leaves decisions about what sort of people should be born in the hands of individual parents, absent government intervention. This ideal in combination with the continued advancement and normalization of ARTs may result in the resurfacing of eugenic ideals in the name of "health" and "healthy babies"—in other words, "politically correct eugenics."

For further discussion, see Seema Mohapatra, "Politically Correct Eugenics," *Florida International University Law Review* 12, (2016): 69–70; Dov Fox, "The Illiberality of 'Liberal Eugenics,'" *Ratio* 20, No. 1, (2007): 1–25.

A final source of health disparity relates to knowledge about health and medicine. Genetic technologies that screen embryonic and fetal genomes, including PGT and comprehensive chromosome screening, potentially allow greater insight into the health outcomes of a child.[42] However, using these technologies to further one's reproductive values depends largely on parental education and knowledge. There is a positive correlation between education and socioeconomic status, health, and access to medical care. For example, as levels of education increase, incidences of infertility decline.[43] Because marginalized groups are more likely to be economically disadvantaged, they are more likely to lack access to information about their health-care opportunities. Studies have found that African Americans and Latinos tend to have lower knowledge overall about genetic testing technologies than non-Hispanic whites.[44] Further, the general belief is that women with more education are more likely to accept a recommendation for such genetic screening during fertility care or pregnancy.[45] This problematizes how medical institutions disperse knowledge about such technologies, who is framed as a target patient, and the social disparities resulting from prioritizing health outcomes for those who are already more educated. With access to the predictive power of genetic testing during assisted reproduction, those who have the educational capital to navigate complex medical procedures and results are more able to harness the medical system to further their reproductive values.

In the United States, most users of ART are white and upper-middle class.[46] Because the costs associated with CRISPR germline editing will be even higher than existing ARTs, users of gene editing technologies for reproductive purposes will likely also predominantly be of the same demographic, further widening the gap between those who have access to ARTs and those who do not.[47] If ARTs pave the way for greater acceptance toward gene editing technologies like CRISPR, it is likely that similar race and class patterns will persist and worsen. When considering how class works in tandem with race, with those of marginalized groups being systemically denied economic opportunities for upward mobility, the effects of unequal access to ARTs further disadvantages women and families of color using medicine to recreate a "politically correct" eugenics effort.[48]

Social and Health Inequities Related to ART Use

EXISTING ARTS give those who may not be able to conceive children conventionally opportunities to conceive. They can also help achieve many of the reproductive goals that proponents of CRISPR want to use germline editing for. Despite many of the positive effects ARTs have had on individual lives and families, certain uses of ARTs can also reinforce problematic social norms and health disparities. ARTs are consistently and systematically implemented in ways that perpetuate harmful social hierarchies and normalize society's aspirations toward engineering "health."

Normalizing the Pursuit of the Ideal Family and the Rise of Boutique Medical Markets

The ART market enables parents to pursue an idealized family with socially desirable traits in their children. This pursuit of idealized families is rooted in the reality that Western traits and characteristics lend an individual social capital and privilege. Even though many of these technologies *cannot* guarantee outcomes regarding physical appearance, ability, or intelligence in the resulting offspring, many fertility clinics profit off claims that such outcomes can be achieved. These promises around reproducing children with "desirable" traits normalize social obsession with Western norms of beauty and physical superiority.

For example, preimplantation genetic diagnosis allows parents to screen for characteristics like sex, and egg and sperm donors are "marketed" based on physical

Preferred Characteristics of Gamete Donors:

Egg Donors	Sperm Donors
Feminine attractiveness	Masculine attractiveness
Altruism	Professional aptitude
Tallness	Breadwinning
Athleticism	Paternal pragmatism
Education	

Across research, we see that donors are selected based on skin color, height, and education or employment achievements. Studies have shown that "preferred external features" that resemble "Europeanness" such as light skin and small noses determine egg donor desirability. Donors are also selected based on upper-class resembling values, which includes racial and caste-based markers.

Sources:
Rene Almeling, *Sex Cells: The Medical Market for Eggs and Sperm* (Berkeley: University of California Press, 2011).

Meghna Mukherjee, "How Do You Want Your Eggs? The Medical Management of Kin-Making and Reproductive Inequalities in the United States and India," *Social Problems*, (2022).

appearance and educational attainment (with the assumption that a child would inherit the donor's physical traits and "intelligence"). In particular, sex selection is a common use of PGT and is largely condoned as "family balancing" in the United States, although many other countries prohibit this practice. A 2017 survey of US fertility clinics showed that almost 73% of clinics offer sex selection via PGT, and of those approximately 94% performed sex selection for family balancing and "81% performed selection for 'other elective purposes.'"[49] Studies also show that patients' use of PGT for sex selection has increased consistently.[50] This is an especially harmful technique in societies[51] where the preference for male children remains acute.[52] Beyond sex selection, PGT has also been marketed for cosmetic purposes[53] such as eye color, hair color, and aesthetic build.[54]

Increased social acceptance of parents pursuing an ideal family has resulted in the increased commercialization of egg donation, with egg donation agencies profiting off parents' desires to have children with certain characteristics that will privilege them in a Western society. The fertility industry has been criticized for being a "boutique" medical service for those from wealthier—and whiter—communities, valuing its gamete donors accordingly. Studies about egg and sperm agencies show that gametes are often marketed based on westernized gendered idealizations—egg donors' maternal altruism or sperm donors' financial breadwinning potential.[55] Referred to as "gendered eugenics," fertility markets prioritize egg donors who present feminine and socioeconomically desirable personas by "Western" standards, including tallness, athleticism, educational attainment, and an altruistic desire to help create families.[56] Egg donation agencies often function as businesses that encourage women to ask "top dollar for their high IQs or good looks," framing reproduction as a consumer choice. Where gametes may have once been seen as medical opportunities for fertility, they are increasingly being promoted as the "best product" for those intended parents who can afford them on the marketplace.[57] The value of donated eggs is shifting from a medical necessity to a commodified social product, with emphasis placed on the genetic history of the donor and their physical characteristics.

Selling gametes as consumer products teases the uncomfortable line of reducing one's health, social success, and almost every marker of identity to one's genetics, and putting these up for purchase. Reducing human traits to purchasable commodities suggests that, for the right price, one can create the "perfect" human, implying that there is such a standard to be bought and achieved. Viewing reproduction as solely a commodified exchange significantly devalues human life; moreover, this approach completely neglects that we exist in a web of social structures that systemically afford or deny opportunities for social advancement to individuals who are poor, disabled, of color, or otherwise outside dominant white middle-class norms.

Discriminating against People with Disabilities

Genetic testing of embryos and fetuses to eliminate certain conditions can reinforce discrimination against those with disabilities. In reality, disadvantages individuals may face are often a result of inadequate public infrastructure and unsupportive social accommodations—not anything intrinsic to them as individuals.[58] As seen time and time again in public health studies, an individual's life outcomes rest more on their social and structural conditions than the genetic predispositions they are born with. However, the ways ARTs are implemented do not always reflect this reality.

Use of ARTs can deepen existing stigma and discrimination against those with disabilities and health conditions.[59] The pressure to select a "normal" child serves as a burden and a mechanism of discrimination.[60] Though viewed as enabling parental choice, ARTs can inadvertently restrict parental choice by further stigmatizing disability and a parent's decision to bring to term a fetus with a disability. Information conveyed to parents where testing identified a disabling condition in the embryo or fetus is largely negative and focused on the disability as an ongoing tragic trajectory. Parents are often pressured not to bring to term a fetus or embryo with disabling

Though genetics do play a role in disease, studies show that social factors—such as stable and affordable housing, education, and access to nutritious food—can largely determine health and quality of life.

conditions,[61] and we increasingly see pregnant people aborting fetuses with genetic conditions.[62] [63] There is also a pattern of medical professionals labeling women who refuse to terminate fetuses or embryos that will become a child with a genetic condition or disability as "bad" or "irresponsible" mothers.[64] When prospective parents are advised to select against a fetus because of predicted disability, they are often misinformed that their disabled child will not fulfill what they seek in child rearing.[65]

In contrast, parents who are provided information about resources and social supports for a child with a disability report far more positive experiences with their medical providers.[66] Rather than facing agonizing experiences, families of children with disabilities on average fare "no better or worse than families in general."[67] Although there are undoubtedly challenges to raising a child with a disability—such as having to deal with environmental barriers and lack of services and resources—these families ultimately flourish and show no difference in parents' stress levels, family functioning, and marital satisfaction.[68]

The pursuit of Western standards of perfection through ARTs is rooted in the misperception that quality of life is determined by genetics rather than social circumstances. Though genetics do play a role in disease, studies show that social factors—such as stable and affordable housing, education, and access to nutritious food—can largely determine health and quality of life.[69] When a health problem is expressed in genetic rather than social terms, the source of the problem is the biology of the individual, and social inequalities escape blame.[70] This conflation of social problems with biological problems serves to absolve our society from making meaningful structural changes to improve human quality of life; it also results in the further subordination of people with disabilities (and other marginalized communities) because it fails to acknowledge the ways in which capitalism, racism, and ableism disable and oppress people.

How Would CRISPR Exacerbate Existing ART Inequalities?

IF USED TO EDIT human germ cells or embryos for reproduction, CRISPR would be part of assisted reproduction, and would exacerbate all the social inequities that ARTs engender, as outlined above. Moreover, germline editing has the potential to further entrench these problems due to the nature of the technology and its inevitable high cost.

First, CRISPR's high cost would increase inequality by allowing the wealthy to purchase generational privilege in an unprecedented way. ARTs are already prohibitively expensive, and as such, most users of ART in the United States are white and upper-middle class. CRISPR stands to be even more expensive, meaning that access to this technology would be more inequitable. Consequently, there is a concern that poor women and women of color will be "left out of this 'genetic revolution,'" due to a lack of access to this technology.[71] A larger social consequence of this could be disability becoming more concentrated in poor and minority communities—communities that already lack supportive public infrastructure. Disability cannot be eliminated using genetic technologies because environments are disabling. Thus, proposing to eliminate disability without addressing underlying social inequities is not only harmful but untenable. Most importantly, people with disabilities will continue to be a part of our communities and make valuable contributions, and these communities deserve support to thrive. Those privileged enough to access CRISPR technology would not only purchase capacity and privilege for their children, but for their children's descendants as well, ensuring that the divide between the have and have-nots would become ever more pronounced.

How Would CRISPR Exacerbate Existing Inequalities?

1. Unknown and heightened risks from CRISPR could worsen health outcomes for individuals resulting from edited embryos
2. Cost and health literacy requirements would likely exclude many low-income individuals of color from utilizing this technology
3. Normalization of this technology would result in greater neglect of structural underpinnings of disability
4. Enhancements would shift how we value existence, define normalcy, and reach eugenics

Second, CRISPR's precision and safety are often overstated and misleading. The current state of the technology could result in unexpected harmful health outcomes for those born of edited embryos. Existing ARTs are not without risk. However, when used to edit the germline, CRISPR is both redundant and even riskier than existing ARTs. Germline editing would entail a high risk of unintended consequences and inadvertent changes,[72] and even if a gene is

Studies have shown that pregnancies resulting from ARTs are associated with a

higher risk of pregnancy complications

compared with spontaneously conceived pregnancies. For example, an analysis of almost 66,000 live births found an increased risk of preterm birth and low birthweight with very high number of oocytes following IVF.

Source: A. La Marca, Y. Khalaf, P. T. Seed, and S. K. Sunkara, "Live Birth and Perinatal Outcomes following Stimulated and Unstimulated IVF," *Human Reproduction* 30, No. 6, (2015): 1473–1480.

perfectly targeted, its long-term effects of mutations are unknown.[73] Proponents of germline editing may argue that CRISPR is more "precise" than existing genetic technologies and ARTs, allowing parents to choose specific physical traits for their children. But this is not the case, as genetic expression and health outcomes are far more complex than the presence of certain genes[74] and are also predicated on environmental interactions.[75] Overall, this means that existing ARTs and CRISPR genetic technologies can only do so much in the reproductive context.

Germline editing has the dangerous potential to alter human embryos beyond what existing ARTs are capable of. While existing ARTs only allow parents to pick from unedited embryos (where genetic composition reflects natural biological processes upon sperm and egg fertilization), germline editing can enable selective genetic enhancements that require technological intervention to produce. These enhancements could include enriched intelligence, physical strength, and height, as well as modifications to personality, "moral character," or characteristics such as impulse control and memory.[76] In fact, some proponents of genome editing argue that humans have a "moral obligation" to enhance the human race in this way.[77] However, using medical techniques to "produce children who are claimed to be superior because of their particular genes" risks radically shifting our society's construction of "normalcy" and introducing new sources of discrimination.[78] For example, individuals who have been edited for enhanced intelligence may be treated differently based on social perceptions of their intelligence, regardless of whether the editing actually resulted in increased intelligence. In other words, regardless of the actual success of such promised enhancements, individuals whose genes were modified would likely have predetermined life prospects as well as social privilege imbued in the value of their DNA. Individuals who have been edited to have certain skills may also suffer in the face of predetermined life prospects that do not align with their strengths, interests, and desires that naturally emerge during one's life course, limiting their individuality and potential.[79]

In a world where health is narrowly defined through gene editing, individual difference for those who cannot or do not partake in genome engineering will be reframed as individual disadvantage, a "shortcoming" of one's genetic heritage, shaping future generations that are fundamentally unequal.[80]

Looking Forward

PUBLIC DISCOURSE FAILS to contextualize the likely effects of CRISPR when used as an ART. However, it is clear that when used for reproductive purposes, gene editing will exist within the same market pressures and unequal social systems as ARTs, and as such will likely further the same racist, ableist, and classist agendas. The difference is that while ARTs currently allow for valuable reproductive possibilities with relatively well-understood risks, heritable genome editing would—in its best-case scenario, as restricted to medical reproductive purposes—exacerbate risks and harmful social consequences while offering little to no change in reproductive possibilities currently available. Germline gene editing could have permanent repercussions on the human race. If used for reproduction, gene editing might further entrench social inequalities and problematic conceptions of family, health, and normalcy.

Genetically modifying embryos at best further complicates existing ethical questions around ARTs. At its worst, genome editing can irreversibly alter humanity under a eugenicist vision. If allowed, use of germline editing technology would inevitably result in the wealthy and privileged ensuring that their offspring are genetically "enhanced"—but only by virtue of being able to define for themselves which traits are superior by selecting for them. Proponents argue reproductive use of CRISPR will bolster parental autonomy[81] to select the "best" futures for their children.[82] However, the reality of this technology is that it would narrow and alter our society's conception of normal and desirable existence, stigmatizing the diversity that so importantly enriches our communities.[83]

Recommendations

1. **Global ban and sanctions on germline editing of embryos for reproductive purposes**
2. **Global regulations**
3. **Bans against fertility tourism enabling CRISPR use**

The ethical implications of germline embryo editing are severe and irreversible. And, with Dr. He Jiankui having already created and genetically edited three embryos, now children, using CRISPR, there is an urgent need to establish stringent guidelines and consequences for such actions within the scientific community. As such, we argue for a global ban on germline editing of embryos for reproductive purposes. We call for severe sanctions on clinical and laboratory experimentation that support development of germline editing techniques that lead to genetically modified children and practices toward this end.

Genome editing of embryos must be regulated

distinctly from other ARTs because of the unique effect such editing can have. Unlike reproductive technologies in current use, which are already difficult to regulate in many countries, genome editing technology must be regulated on a universal, global scale (i.e., treaties, international laws and sanctions). The dilemma of regulating genome editing in embryos is much more akin to the regulation of cloning technology or nuclear weapons, in that editing of the germline anywhere in the world would have severe and irreversible consequences on the human genome and consequently for humanity at large. As such, global consensus must outweigh individual national interests, and scientists cannot be left to regulate themselves. The birth of the CRISPR-edited babies under Dr. He Jiankui's direction, in violation of the long-standing international consensus against human germline editing for reproduction, demonstrates that self-regulation is not viable.

As such, we argue for a global ban on germline editing of embryos for reproductive purposes. We call for severe sanctions on clinical and laboratory experimentation that support development of germline editing techniques that lead to genetically modified children and practices toward this end.

The mainstream perspective of proponents of germline editing is that reproductive CRISPR can be regulated and limited to the treatment of specific genetic diseases. However, the market context in which heritable genome editing would exist alongside ARTs suggests that such regulation would be difficult, if not unfeasible to enforce. In the United States, much of the fertility industry is privatized and tied to the consumer market.[84] This industry is also growing at a rapid pace. As technology and the opportunity for profit outpace the establishment of regulatory frameworks (e.g., the Food and Drug Administration currently cannot regulate "off-label" uses of products), profit and consumer preferences remain a driving force behind the services offered by fertility clinics in the United States. We consistently see profit overtake clinical value, with new companies directly targeting parents to screen their embryos for conditions like heart disease and diabetes despite the unvalidated science behind such testing.[85] Given the way existing ARTs continue to be used, it does not seem reasonable to assume that reproductive CRISPR would be regulated more safely or responsibly than current practices.

The uneven regulation of ARTs globally and within the United States is also predictive of the repercussions of not having a global ban on human germline editing—that is, the creation of markets in countries with less regulation. Fertility tourism, wherein people travel abroad to access fertility treatments, is already a global dilemma.[86] Legal restrictions, discrimination, and cost of fertility treatments are the driving forces

Over 70 countries

have already passed complete bans on heritable genome editing, and

29 countries

have ratified the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (or the Oviedo Convention), which prohibits heritable human genome editing and is legally binding on the nations that have ratified it.

behind fertility tourism, which raises a number of ethical and social dilemmas.[87] Patients accessing aggressive fertility treatments in countries with less regulation around ARTs are often at a high risk of medical side effects and complications. Similarly, in countries that do not regulate ARTs as closely, or that have illegal black markets for ARTs, donors and surrogates may also face more exploitation due to financial desperation, inadequate medical care, or forceful participation against their will.[88] Similarly, if genome editing is banned in some countries but not others, those who can afford to do so could travel to have access to this technology. This raises the novel concern that the human genome would be permanently altered regardless of efforts by individual countries to prohibit its use. When genome editing occurs anywhere in the world, it affects all of humanity—not just the individuals in one country.

Though a global ban on germline editing may seem impossible, the reality is that there is unprecedented global consensus on preventing the use of this technology. Over seventy countries have already passed complete bans on heritable genome editing, and twenty-nine countries have ratified the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (or the Oviedo Convention), which prohibits heritable human genome editing and is legally binding on the nations that have ratified it.[89] Global consensus around this technology is already forming, and if access to this technology becomes a reality in parts of the world, it is more important than ever to affirm a universal ban and enforcement strategy reflecting this consensus.

Once the line has been crossed, and the technology has been used, there may be no turning back because commercial interests will be too powerful to resist or regulate. If brought into the reproductive health space, genetic engineering via CRISPR would offer a market opportunity for those with purchasing power to selectively reproduce privilege in future generations.[90] This would reframe social privileges and health outcomes as being undeniably naturalized and biologically heritable. It would also starkly neglect the vast research on structural health inequalities, genetic complexity, and gene-environment interactions. Taken together, reproductive use of CRISPR would reify harmful social hierarchies based on human biological and social diversity that instead ought to be celebrated.[91] The international community must make the difficult and pressing decision to prioritize the preservation of the common good over individual interests.

Endnotes

1 A. Powell, "CRISPR's Breakthrough Implications," *The Harvard Gazette,* May 16, 2018, retrieved from https://news.harvard.edu/gazette/story/2018/05/crispr-pioneer-jennifer-doudna-explains-gene-editing-technology-in-prather-lectures/.

2 M. Hiltzik, "CRISPR Pioneer Jennifer Doudna Struggles with the Ethical Implications of What She Has Wrought," *The Los Angeles Times*, July 21, 2017, retrieved from https://www.latimes.com/business/hiltzik/la-fi-hiltzik-doudna-20170721-story.html.

3 E. Yong, "A Reckless and Needless Use of Gene Editing on Human Embryos," *The Atlantic*, November 26, 2018, retrieved from https://www.theatlantic.com/science/archive/2018/11/first-gene-edited-babies-have-allegedly-been-born-in-china/576661/.

4 Yong, "A Reckless and Needless Use."

5 J. Savulescu, "Genetic Interventions and the Ethics of Enhancement of Human Beings," *The Oxford Handbook of Bioethics* (2007): 516–535.

6 A. Regalado, "Engineering the Perfect Baby," *MIT Technology Review*, March 5, 2015, retrieved from https://www.technologyreview.com/2015/03/05/249167/engineering-the-perfect-baby/.

7 K. Megget, "Money from Genes: CRISPR Goes Commercial," *Scientific American*, January 22, 2015, retrieved from https://www.scientificamerican.com/article/money-from-genes-crispr-goes-commercial/.

8 H. Ledford, "CRISPR Gene Editing in Human Embryos Wreaks Chromosomal Mayhem," *Nature*, June 25, 2020, retrieved from https://www.nature.com/articles/d41586-020-01906-4.

9 WINFertility, "PGD v. PGS," *WINFertility* (2020), retrieved from https://www.winfertility.com/blog/pgd-vs-pgs/.

10 Gay Becker, Anneliese Butler, and Robert D. Nachtigall, "Resemblance Talk: A Challenge for Parents Whose Children Were Conceived with Donor Gametes in the US," *Social Science and Medicine* 61, No. 1, (2020): 1300–1209.

11 B. Cwik, "Revising, Correcting, and Transferring Genes," *The American Journal of Bioethics* 20, No. 8, (2020): 7–18.

12 M. Zafer, H. Horvath, O. Mmeje, S. van der Poel, A. E. Semprini, G. Rutherford, and J. Brown, "Effectiveness of Semen Washing to Prevent Human Immunodeficiency Virus (HIV) Transmission and Assist Pregnancy in HIV-Discordant Couples: A Systematic Review and Meta-analysis," *Fertility and Sterility*, 105, No. 3, (2016): 645–655.e2, doi.org/10.1016/j.fertnstert.2015.11.028.

13 K. Roche, C. Racowsky, and J. Harper, "Utilization of Preimplantation Genetic Testing in the USA," *Journal of Assisted Reproduction and Genetics* 38, (2021): 1045–1053.

14 S. Cooke-Huble and V. Maddalena, "Access to Genetic Testing and Genetic Counseling in Vulnerable Populations: The d/Deaf and Hard of Hearing Population," *Journal of Community Genetics* 2, No. 3, (2011): 118–19.

15 K. Kissil and M. P. Davey, "Health Disparities in Procreation: Unequal Access to Assisted Reproductive Technologies," *Journal of Feminist Family Therapy* 24, No. 3, (2012): 199–200.

16 Dorothy E. Roberts, "Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?" *Signs: Journal of Women in Culture and Society* 34, No. 4, (2009): 783–804, doi:10.1086/597132.

17 Kissil and Davey, "Health Disparities in Procreation," 198.

18 "Infertility," World Health Organization (2020), accessed 2022 at https://www.who.int/news-room/fact-sheets/detail/infertility.

19 A. C. Dieke, Y. Zhang, D. M. Kissin, W. D. Barfield, and S. L. Boulet, "Disparities in Assisted Reproductive Technology Utilization by Race and Ethnicity, United States, 2014: A Commentary," *Journal of Women's Health (Larchmt)* 26, No. 6, (2017): 605–608.

20 Kissil and Davey, "Health Disparities in Procreation," 199.

21 Dieke et al., "Disparities in Assisted Reproductive Technology Utilization," 605–608.

22 Kissil and Davey, "Health Disparities in Procreation," 198.

23 Kissil and Davey, "Health Disparities in Procreation," 199.

24 "The Hastings Center—Assisted Reproduction," The Hastings Center (2020), accessed 2020 at https://www.thehastingscenter.org/briefingbook/assisted-reproduction/.

25 "State Laws Related to Insurance Coverage for Infertility Treatment," National Conference of State Legislatures (2021), https://www.ncsl.org/research/health/insurance-coverage-for-infertility-laws.aspx.

26 A. Klein, "I.V.F. Is Expensive. Here's How to Bring Down the Cost," *New York Times*, April 18, 2020, retrieved from https://www.nytimes.com/article/ivf-treatment-costs-guide.html.

27 Kissil and Davey, "Health Disparities in Procreation," 199–200.

28 L. King and M. H. Meyer, "The Politics of Reproductive Benefits: U.S. Insurance Coverage of Contraceptive and Infertility Treatments," *Gender & Society* 11, No. 1, (1997): 26.

29 J. Walls, K. Gifford, U. Ranji, A. Salganicoff, and I. Gomez, "Medicaid Coverage of Family Planning Benefits: Results from a State Survey," Kaiser Family Foundation (2016), retrieved from https://www.kff.org/report-section/medicaid-coverage-of-family-planning-benefits-results-from-a-state-survey-fertility-services/.

30 King and Meyer, "The Politics of Reproductive Benefits," 8, 26.

31 Kissil and Davey, "Health Disparities in Procreation," 200.

32 World Health Organization, "Infertility."

33 The Hastings Center, "The Hastings Center—Assisted Reproduction."

34 Kissil and Davey, "Health Disparities in Procreation," 200–202.

35 Z. Luna and K. Luker, "Reproductive Justice," *The Annual Review of Law and Social Science* 9, (2013): 330–40.

36 Kissil and Davey, "Health Disparities in Procreation," 200–201.

37 Roberts "Race, Gender, and Genetic Technologies," 783–804.

38 Kissil and Davey, "Health Disparities in Procreation," 201.

39 Kissil and Davey, "Health Disparities in Procreation," 200.

40 Kissil and Davey, "Health Disparities in Procreation," 200.

41 Cooke-Hubley and Maddalena, "Access to Genetic Testing," 118–119.

42 G. Maranto, "Review: The Gene Machine: How Genetic Technologies Are Changing the Way We Have Kids—and the Kids We Have," *Biopolitical Times*, July 2, 2018, retrieved from https://www.geneticsandsociety.org/biopolitical-times/review-gene-machine-how-genetic-technologies-are-changing-way-we-have-kids-and.

43 Kissil and Davey, "Health Disparities in Procreation," 198.

44 Cooke-Hubley and Maddalena, "Access to Genetic Testing," 122.

45 H. Greely, "Get Ready for the Flood of Fetal Genetic Testing," *Nature* 469, (2011): 290.

46 S. Mohapatra, "Politically Correct Eugenics," *Florida International University Law Review* 12, (2016): 69–70.

47 Mohapatra, "Politically Correct Eugenics," 69–70.

48 Mohapatra, "Politically Correct Eugenics," 69–70.

49 Sarah M. Capelouto et al., "Sex Selection for Non-medical Indications: A Survey of Current Pre-implantation Genetic Screening Practices among U.S. ART Clinics," *Journal of Assisted Reproduction and Genetics* 35, No. 3, (2018): 409–416, doi:10.1007/s10815-017-1076-2.

50 Elizabeth S. Ginsburg et al., "Use of Preimplantation Genetic Diagnosis and Preimplantation Genetic Screening in the United States: A Society for Assisted Reproductive Technology Writing Group Paper," *Fertility and Sterility* 96, No. 4, (2011): 865–868.

51 S. Puri, V. Adams, S. Ivey, and R. D. Nachtigall, "There Is Such a Thing as Too Many Daughters, but Not Too Many Sons: A Qualitative Study of Son Preference and Fetal Sex Selection among Indian Immigrants in the United States," *Social Science & Medicine* 72, No. 7, (2011): 1169–1176.

52 Lauren R. Roth, "Reproductive Selection Bias," *Health Matrix* 27 (2017): 263.

53 G. Naik, "A Baby, Please. Blond, Freckles—Hold the Colic," *The Wall Street Journal*, February 12, 2009, retrieved from https://www.wsj.com/articles/SB123439771603075099.

54 *The Fertility Institutes,* The Fertility Institutes (n.d.), retrieved December 1, 2021, from https://www.fertility-docs.com/index.php.

55 Rene Almeling, *Sex Cells: The Medical Market for Eggs and Sperm* (Berkeley: University of California Press, 2011).

56 Cynthia R. Daniels and Erin Heidt-Forsythe, "Gendered Eugenics and the Problematic of Free Market Reproductive Technologies: Sperm and Egg Donation in the United States," *Journal of Women in Culture and Society* 37, No. 3, (2012): 719–747.

57 M. S. Frankel, "Inheritable Genetic Modification and a Brave New World: Did Huxley Have It Wrong?" *The Hastings Center Report* 33, No. 2, (2003): 31–36.

58 Ingunn Moser, "Disability and the Promises of Technology: Technology, Subjectivity and Embodiment within an Order of the Normal," *Information, Communication & Society* 9, No. 3, (2006): 373–395.

59 Erevelles Nirmala, Anne Kanga, and Renee Middleton, "How Does It Feel to Be a Problem? Race, Disability, and Exclusion in Educational Policy," in *Who Benefits from Special Education*: *Remediating (Fixing) Other People's Children*, Ellen A. Brantlinger ed. (New York: Routledge, 2006).

60 Alison Piepmeier, "Would It Be Better for Her Not to Be Born?: Down Syndrome, Prenatal Testing, and Reproductive Decision-Making," *Feminist Formations* 27, No. 1, (2015): 1–24, doi:10.1353/ff.2015.0004.

61 A. Lippman and B. S. Wilfond, "Twice-Told Tales: Stories about Genetic Disorders," *American Journal of Human Genetics* 51, No. 4, (1992), 936–937.

62 J. L. Natoli, D. L. Ackerman, J. G. Edwards, and S. McDermott, "Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)," *Prenatal Diagnosis* 32, No. 2, (2012): 142–53.

63 V. Ravitsky, "The Shifting Landscape of Prenatal Testing: Between Reproductive Autonomy and Public Health," *Hastings Center Report* 47, No. S3, (2017): S34–S40.

64 D. Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (New York, London: The New Press, 2011).

65 A. Asch, "Disability Equality and Prenatal Testing: Contradictory or Compatible?" *Florida State University Law Review* 30, No. 2, (2003).

66 Lippman and Wilfond, "Twice-Told Tales," 936–937.

67 A. Asch and E. Parens, "Special Supplement: The Disability Rights Critique of Prenatal Genetic Testing Reflections and Recommendations," *Hasting Center Report* 29, No. S1, S7, (1999).

68 Asch and Parens, "Special Supplement."

69 N. Comfort, "Can We Cure Genetic Diseases without Slipping into Eugenics?" *The Nation*, July 16, 2015, retrieved from https://www.thenation.com/article/archive/can-we-cure-genetic-diseases-without-slipping-into-eugenics/.

70 Comfort, "Can We Cure Genetic Diseases without Slipping into Eugenics?"

71 Mohapatra, "Politically Correct Eugenics."

72 Comfort, "Can We Cure Genetic Diseases without Slipping into Eugenics?"

73 K. Swisher, "Should You Choose Your Baby's Eye Color?" *New York Times,* October 22, 2020, retrieved from https://www.nytimes.com/2020/10/22/opinion/sway-kara-swisher-jennifer-doudna.html?showTranscript=1.

74 Abby Lippman, "Led (Astray) by Genetic Maps: The Cartography of the Human Genome and Health Care," *Social Science & Medicine* 35, No. 12, (1992): 1469–1476.

75 Sara Shostak, "Locating Gene-Environment Interaction: At the Intersections of Genetics and Public Health," *Social Science & Medicine* 56, No. 11, (2003): 2327–2342.

76 Savulescu, "Genetic Interventions," 516–535.

77 Comfort, "Can We Cure Genetic Diseases without Slipping into Eugenics?"

78 Naik, "A Baby, Please. Blond, Freckles—Hold the Colic."

79 M. J. Bayefsky and B. E. Berkman, "Implementing Expanded Prenatal Genetic Testing: Should Parents Have Access to Any and All Fetal Genetic Information?" *The American Journal of Bioethics*, (2021): 1–26, advance online publication at doi.org/10.1080/15265161.2020.1867933.

80 Roberts, "Race, Gender, and Genetic Technologies," 783–804.

81 C. Mills, "Reproductive Autonomy as Self-making: Procreative Liberty and the Practice of Ethical Subjectivity," *The Journal of Medicine and Philosophy* 38, No. 6, (2013): 639–656, doi.org/10.1093/jmp/jht046.

82 Savulescu, "Genetic Interventions," 516–535.

83 Comfort, "Can We Cure Genetic Diseases without Slipping into Eugenics?"

84 The Hastings Center, "The Hastings Center—Assisted Reproduction."

85 G. Lázaro-Muñoz, S. Pereira, S. Carmi, and T. Lencz, "Screening Embryos for Polygenic Conditions and Traits: Ethical Considerations for an Emerging Technology," *Genetics in Medicine* 23, (2020): 432–434.

86 E. Isachenko, V. Isachenko, M. C. Inhom, P. Mallmann, P. Patrizio, G. Rahimi, M. Salama, and L. M. Westphal, "Cross Border Reproductive Care (CBRC): A Growing Global Phenomenon with Multidimensional Implications (a Systematic and Critical Review)," *Journal of Assisted Reproduction and Genetics* 35, (2018): 1277–1288.

87 Isachenko et al., "Cross Border Reproductive Care," 1277–1288.

88 Isachenko et al., "Cross Border Reproductive Care," 1277–1288.

89 F. Baylis, M. Darnovsky, K. Hasson, and T. M. Krahn, "Human Germline and Heritable Genome Editing: The Global Policy Landscape," *The CRISPR Journal* 3, No. 5, (2020): 365–377.

90 Frankel, "Inheritable Genetic Modification," 31–36.

91 Roberts, *Fatal Invention*.

The Othering & Belonging Institute brings together researchers, community stakeholders, and policy-makers to identify and challenge the barriers to an inclusive, just, and sustainable society in order to create transformative change.