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## POLITICALLY CORRECT EUGENICS

Seema Mohapatra\*

### INTRODUCTION

Eugenics is a loaded word bringing to mind the horrors of Nazi Germany and here in the United States, our history of forced sterilizations. Although eugenics has a negative connotation, family balancing (the term of art coined to refer to those who use preimplantation genetic diagnosis to pick an embryo of a certain gender) does not. In fact, it sounds empowering to be able to have a say in the gender of one's baby. This Article explores new innovations in life sciences that make eugenics inevitable—for a certain class of people—those who can afford to pay for it. The designer baby thought experiment has been around for several decades, but until very recently the idea of actually being able to enhance an embryo was still very much science fiction. Enter CRISPR/Cas9, a new technology for editing genes in a cell's DNA—which was heralded in late 2015 by the Journal *Science* as the “Breakthrough of the Year.” Although gene editing has been around since the 1970's, until the advent of CRISPR/Cas9,<sup>1</sup> it was very difficult and had low success rates. CRISPR/Cas9 has the potential to make gene editing much simpler and eventually cheaper. In the next few decades, we can expect this technology to be used in conjunction with in vitro fertilization to help ensure that a fetus be free of certain diseases, have certain physical characteristics, and possibly even more. Just this month, the first baby was born free of mitochondrial disease using mitochondrial replacement. This Article uses these two types of scientific breakthroughs to demonstrate how the new eugenics is not deemed horrific—but rather as a savior of good health. Due to commercial pressures (often driven by consumer-patients, who want autonomy in health care, particularly in the realm of baby-making), we are unlikely to see legal roadblocks to having healthier, or even designer babies in the United States. In this Article, I will lay out why I believe that the wild west of assisted

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<sup>1</sup> At the time of this writing CRISPR/Cas9 is the most “promising” gene editing technology. However, the science in this area is moving very fast. NgAgo is another gene editing technology that we may begin hearing more about in the years to come.

reproduction will lead to the acceptance of gene editing, mitochondrial replacement, and whatever gene manipulation comes next. My main focus is on how these developments are likely to affect minorities and the poor, who will not be able to afford this technology. Using a reproductive and disability justice frame, I analyze how the acceptance of a politically correct eugenics—through the acceptance of these types of technologies—may affect and further disadvantage women of color and families of color.

This Article first provides a very basic overview about two scientific advances that are currently being researched that while exciting and promising, have the very real possibility of allowing eugenic ideals to resurface innocuously—all in the name of good health and healthy babies. These two advances are gene editing and mitochondrial replacement, which has been wrongly called in the media as “three-parent embryos.” My purpose in introducing these new technologies is to show how quickly science is changing in the name of good health, without considering what effect these scientific changes may have on disadvantaged populations. This Article is not calling for any kind of ban or even halting of the scientific process. I try to examine how the use of these scientific techniques may advantage certain groups and disadvantage others. I suggest that examining these issues with a reproductive justice and disability justice frame will help ensure that unheard and underrepresented voices are considered in the march towards protecting health. To that end, this Article progresses as follows: Part I provides a background on eugenics and the eugenics movement. Part II explores gene editing technology and mitochondrial replacement research. The purpose of this section is to show what the future possibilities are in terms of preventing diseases in embryos. Part III describes how this new scientific progress could lead to a greater embrace of eugenic thinking—one that does not carry the stigma of the eugenic past. Finally, Part IV analyzes how examining these potential advances from a reproductive and disability justice frame may allow for inclusion of less powerful and vulnerable groups in the discussion about the future of reproduction.

## I. EUGENICS THEN

This Part I describes eugenic philosophy and how eugenics operated in the United States. Eugenics justified many historical horrors—such as forced and coerced sterilizations. At the time, though, eugenicists genuinely felt that they were scientifically improving society. Sir Francis Galton, a first cousin to Charles Darwin, is credited with coining the term

“eugenics.”<sup>2</sup> Galton defined eugenics as “the science of improving stock . . . to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had.”<sup>3</sup> Eugenicists believed that whites were superior and Galton himself believed that Blacks possessed inheritable “intellectual inferiority” and “impulsive passions.”<sup>4</sup> The idea behind the eugenics movement was to increase society’s “desirables” and get rid of its “undesirables.”<sup>5</sup> Although Galton’s ideas were initially not embraced, they became more popular as Darwin’s theory of evolution and survival of the fittest became more accepted.<sup>6</sup> Additionally, in Europe, numerous educated professionals embraced the eugenics theory, which led it more credence worldwide.<sup>7</sup> Similarly, in the United States, eugenic beliefs were held by high profile and well respected intellectuals, such as Alexander Graham Bell and Francis Crick, Theodore Roosevelt and Margaret Sanger.<sup>8</sup> This allowed eugenics to gain legitimacy in both science and politics. In fact, geneticists were often eugenicists, with “five of the first six presidents of the American Society of Human Genetics, serv[ing] simultaneously as members of the board of directors of the American Eugenics Society (AES).”<sup>9</sup> Nicholas Agar coined the term “liberal eugenics” referring to the good that can be done through genetic engineering being used to improve the prospects associated with a person’s life. Julian Savluescu had argued the term he referred to as “procreative beneficence” with regards to the people that are able to improve the quality of life having the obligation to actually do so.<sup>10</sup> This section focuses on the United States’ historical experience with eugenics to set a backdrop for how it is similar and different to the new politically correct eugenics of the future.

Unlike the state massacre of undesirables in Nazi Germany, eugenics

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<sup>2</sup> Daniel J. Kelves, *The History of Eugenics*, in INTERNATIONAL SUMMIT ON HUMAN GENE EDITING COMMISSIONED PAPERS, 10–12, [http://www.nationalacademies.org/cs/groups/pgasite/documents/webpage/pgs\\_170455.pdf](http://www.nationalacademies.org/cs/groups/pgasite/documents/webpage/pgs_170455.pdf) (last visited Oct. 1, 2016).

<sup>3</sup> FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT 17 n.1 (Gavan Tredoux ed., 2d ed. 1907), <http://galton.org/books/human-faculty/text/galton-1883-human-faculty-v4.pdf>.

<sup>4</sup> Anna Zaret, *Editing Embryos: Considering Restrictions on Genetically Engineering Humans*, 67 HASTINGS L. J. 1805, 1822 n.24 (2016).

<sup>5</sup> Kelves, *supra* note 2, at 9.

<sup>6</sup> Bret D. Asbury, “Backdoor to Eugenics”? *The Risks of Prenatal Diagnosis for Poor, Black Women*, 23 DUKE J. GENDER L. & POL’Y 1, 5 (2015).

<sup>7</sup> *Id.*

<sup>8</sup> Nicholas G. Evans & Jonathan D. Moreno, *Children of Capital: Eugenics in the World of Private Biotechnology*, 6 ETHICS IN BIOLOGY, ENGINEERING & MED. 283, 286 (2016).

<sup>9</sup> Asbury, *supra* note 6, at 1.

<sup>10</sup> Evans & Moreno, *supra* note 8, at 284.

in the United States often proceeded in an ostensibly altruistic, but hardly less morally repugnant, manner.<sup>11</sup> We can see the effect of eugenic ideals in the legislative policies of the United States. As a result of eugenic philosophy articulated by leadership at the Eugenics Record Office, the Immigration Restriction Act of 1924 (IRA) was passed.<sup>12</sup> Essentially, the IRA “closed the borders to immigrants unless they were Protestants from Northern Europe.”<sup>13</sup> This was in keeping with the eugenic ideal of keeping bloodlines “pure.”

Eugenics also justified a variety of family laws in the United States, including laws prohibiting marriages between those of mixed races, of the “feeble-minded,” alcoholics, criminals, and those with venereal diseases.<sup>14</sup> There were laws passed starting in Indiana in 1907 that mandated sterilizations of the same categories of undesirables. In *Buck v. Bell*, Justice Holmes upheld such forced sterilization in one of the most regrettable Supreme Court decisions of all time. He declared that “three generations of imbeciles are enough.”<sup>15</sup> Thus, *Buck v. Bell* essentially allowed compulsory sterilization of the “unfit,” as it was defined in that time period. This allowed the practice of state enforced sterilization to continue through the 1980’s. In 1935, the largest number of states (twenty-seven) mandated some form of eugenic sterilization.<sup>16</sup> Even as late as 1981, the Oregon State Board of Social Protection (formerly known as the Oregon State Board of Eugenics) performed compulsory sterilizations.<sup>17</sup> By 1960, almost 60,000 Americans were sterilized without their consent. Not all people were affected the same way by forced sterilizations. Those who were sterilized under these laws were disproportionately black.<sup>18</sup>

Although eugenics is often thought of as only state sponsored, eugenic idealism went far beyond the government. Eugenic ideals were embraced by medical and professional societies. Starting in the early days of eugenics in the United States, there was an emphasis on race and limiting Black reproduction. In 1939, the “Negro Project,” was led by Margaret Sanger, who headed the Birth Control Foundation of America (BCFA).<sup>19</sup> Sanger gathered the support of numerous black leaders including W.E.B. DuBois, Adam Clayton Powell, Mary McLeod Bethune and, years later, even Dr.

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<sup>11</sup> Asbury, *supra* note 6, at 5.

<sup>12</sup> *Id.*

<sup>13</sup> *Id.* at 5–6.

<sup>14</sup> *Id.*

<sup>15</sup> *Buck v. Bell*, 274 U.S. 200, 208 (1927).

<sup>16</sup> Asbury, *supra* note 6, at 11.

<sup>17</sup> Evans & Moreno, *supra* note 8, at 285.

<sup>18</sup> Asbury, *supra* note 6, at 11.

<sup>19</sup> *Id.* at 10.

Martin Luther King, Jr.<sup>20</sup> Sanger's viewpoint reflected her eugenic beliefs. In the written proposal for the project, Sanger wrote, "[t]he mass of Negroes, particularly in the South, still breed carelessly and disastrously, with the result that the increase among Negroes, even more than among whites, is from the portion of the population least intelligent and fit, and least able to rear children properly."<sup>21</sup> The Negro Project aimed to curb reproduction in the Black population by using Black medical personnel, preachers and ministers, and social workers to convince uneducated Southern Blacks to use contraception.<sup>22</sup> This was fueled by the eugenic belief that this population was unfit to have children.<sup>23</sup>

The media similarly embraced eugenics. There were 1600 popular articles published between 1890 to 1924 portraying eugenics in a positive light.<sup>24</sup> The media coverage of eugenic ideals helped spread the values of eugenics to the American people.<sup>25</sup> For example, at a 1914 Race Betterment Conference, there was a "better babies" contest to judge babies on purportedly objective criteria. This Conference was covered very favorably by the press.<sup>26</sup> Although it may be difficult to appreciate from the perspective of modern times, eugenic philosophy was once embraced by Americans of all political backgrounds.<sup>27</sup> Eugenics was not just a government agenda. Americans were themselves interested in how to create a perfect child that lacked heritable conditions such as feeble-mindedness or alcoholism.<sup>28</sup>

Many deem the height of the eugenics movement to be in the early 1900s, but eugenic ideals in the United States did not ever really go away.<sup>29</sup> In the late 1960s, physicians and the government "systematically targeted poor women for 'family planning' services as part of an anti-poverty and population control agenda."<sup>30</sup> Even as late as the early 1970s, there was a focus on how to eliminate the social ill of poverty in the inner cities and overpopulation. Loretta Ross suggests that in response to the militancy of the civil rights movements, upper and middle class whites focused generally

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<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> Evans & Moreno, *supra* note 8, at 286.

<sup>25</sup> *Id.* at 285.

<sup>26</sup> *Id.* at 286.

<sup>27</sup> *Id.*

<sup>28</sup> *Id.*

<sup>29</sup> *Id.* at 285.

<sup>30</sup> Laura T. Kessler, "A Sordid Case": *Stump v. Sparkman*, Judicial Immunity, and the Other Side of Reproductive Rights, 74 MD. L. REV. 833, 874 (2015).

on how to control the black population.<sup>31</sup> “White Americans held inordinate fears that a growing welfare class of African-Americans concentrated in the inner cities would not only create rampant crime, but exacerbate the national debt, and eventually produce a political threat from majority-black voting blocs in urban areas.”<sup>32</sup> Children borne to poor black single mothers were seen as a blight and thus, there was a concerted focus on how to control black women’s reproduction.<sup>33</sup>

As a result, many laws and regulations were changed with the purpose of curbing black reproduction. Public assistance rules were changed with the support of a report by the Family Law Section of the American Bar Association. “The conclusion of [the] report [was] that . . . the use of incentives to welfare mothers to limit child-bearing should be a primary objective in devising public assistance programs.”<sup>34</sup> Essentially with the support of well-regarded family lawyers, states changed public assistance rules and began adopting welfare rules designed to impose financial disincentives against poor women having more children.<sup>35</sup> In *Dandridge v. Williams*,<sup>36</sup> the Supreme Court held that a Maryland law capping federal welfare benefits at \$250.00 per month regardless of a family’s size or need was constitutional. The federal government went from spending \$4.5 million for birth control in 1967 to \$24 million just four years later in 1971.<sup>37</sup> Due to financial incentives and coercion to undergo sterilizations, approximately two million people underwent sterilization in 1973.<sup>38</sup> Many of these procedures were not with “forged consent forms and falsified medical records—describing sterilizations procedures as merely appendectomies and gall bladder removals.”<sup>39</sup> Because of this, accurate numbers are hard to determine but one study found that in one county in Mississippi, sixty percent of women unknowingly underwent

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<sup>31</sup> Loretta J. Ross, *African-American Women and Abortion: A Neglected History*, 3 J. HEALTH CARE POOR & UNDERSERVED 274, 281–82 (1992).

<sup>32</sup> *Id.* at 281.

<sup>33</sup> See generally DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIFE* (1997).

<sup>34</sup> See Hon. Nanette Dembitz, *Should Public Policy Give Incentives to Welfare Mothers to Limit the Number of Their Children?*, 4 FAM. L.Q. 130, 133 (1970) (article reprinting the final revised version of the second report of the Committee on Law and Family Planning of the Section of Family Law of the ABA).

<sup>35</sup> *Id.* at 133–34.

<sup>36</sup> 397 U.S. 471, 487 (1970).

<sup>37</sup> Kessler, *supra* note 30, at 876. (citing RICKIE SOLINGER, *BEGGARS AND CHOOSERS: HOW THE POLITICS OF CHOICE SHAPES ADOPTION, ABORTION, AND WELFARE IN THE UNITED STATES* 9–10 (2001)).

<sup>38</sup> *Id.* at 876–77.

<sup>39</sup> Asbury *supra* note 6, at 12.

hysterectomies after giving birth in hospitals.<sup>40</sup> Minority women were disproportionately affected by these sterilizations. Black, Native American, Alaska Native, Mexican American and Puerto Rican women were sterilized in large numbers in the 1970s without their knowledge or consent.<sup>41</sup> Eugenic thinking led to the presumption that these categories of women would reproduce and then seek state or federal assistance, and thus sterilization was a wise economic choice, regardless of the fact that these women were not even given an opportunity to object.

*Relf v. Weinberger*, a case filed by the Southern Poverty Law Center in 1973, was a particularly egregious, but also sadly representative case of the eugenic times.<sup>42</sup> Minnie Lee (who was twelve-years-old) and Mary Alice Relf (who was fourteen-years-old) were sterilized without their mother's knowledge or consent. "Their mother, who had very little education and was illiterate, signed an 'X' on a piece of paper, expecting her daughters, who were both mentally disabled, would be given birth control shots."<sup>43</sup> The girls and their older sister had been receiving birth control injections prior to this incident.<sup>44</sup> Instead, the young girls were taken from a doctor's office to the hospital and left by themselves.<sup>45</sup> They had no idea what was going on or what would be happening to them. They were placed under general anesthesia and surgically sterilized.<sup>46</sup> Their older sister escaped surgical sterilization by locking herself in her room when her sisters were taken to the hospital.<sup>47</sup> In *Relf v. Weinberger*, the district court found that approximately "100,000 to 150,000 low-income persons ha[ve] been sterilized annually under federally funded programs."<sup>48</sup> The court also found minors were sterilized with federal funds and thousands of poor people "have been improperly coerced into accepting a sterilization operation under the threat that various federally supported welfare benefits would be withdrawn. . . ."<sup>49</sup> The district court judge prohibited this practice and declared that the federal regulations that allowed the use of federal

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<sup>40</sup> *Id.*

<sup>41</sup> Elizabeth J. Chen, *Restoring Rights for Reproductive Justice*, 22 AM. U. J. GENDER SOC. POL'Y & L. 281, 296 (2014).

<sup>42</sup> Kessler, *supra* note 30, at 879.

<sup>43</sup> SOUTHERN POVERTY LAW CTR., *Relf v. Weinberger: Sterilization Abuse*, <https://www.splcenter.org/seeking-justice/case-docket/relf-v-weinberger>.

<sup>44</sup> See Complaint at 8, *Relf v. Weinberger*, 372 F. Supp. 1196 (D.D.C. 1974) (No. 1557-73).

<sup>45</sup> See *id.* at 8–9.

<sup>46</sup> SOUTHERN POVERTY LAW CTR., *supra* note 43.

<sup>47</sup> Complaint, *supra* note 44, at 10.

<sup>48</sup> *Relf*, 372 F. Supp. at 1199, vacated as moot, 565 F.2d 722 (D.C. Cir. 1977) (*per curiam*).

<sup>49</sup> *Id.* at 1204.



family planning funds in this manner to be “arbitrary and unreasonable.”<sup>50</sup> Therefore, federal law subsequently changed to outlaw payments for sterilization except in rare circumstances.<sup>51</sup> Unfortunately, state governments still had robust sterilization programs after this. In 2013, The Sacramento Bee unearthed 148 unapproved sterilization procedures of female inmates in two California prisons from 2006 to 2010.<sup>52</sup> This is not ancient history. These sterilizations occurred less than a decade ago in a state that many think of as liberal and progressive. This Section provided a backdrop for how eugenic reasoning and control flourished in the United States, but also noted how non-government sources, such as intellectuals, the press, and even the American public (through contests and the likes), embraced the eugenic goal of improvement of social stock. In the next section of the paper, I describe gene editing and mitochondrial replacement, in order to explain how these scientific advances, bring about the specter of eugenics, without the same disgust or horror that exists when we discuss the eugenic past.

## II. THE NEW SCIENCE THAT GIVES RISE TO POLITICALLY CORRECT EUGENICS

This Part provides a description of two much heralded scientific advances—mitochondrial replacement and gene editing via CRISPR/Cas9—in order to set the stage for how acceptance of these types of technologies is leading to an acceptable form of eugenics—the quest for a healthy child.

### *Mitochondrial Replacement (or the Misnamed Three-Parent Baby)*

Mitochondrial replacement has gotten an immense amount of media attention in the last few years, in part because the misnomer it is known by “three-parent baby” is quite compelling.<sup>53</sup> In reality, mitochondrial

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<sup>50</sup> *Id.* at 1204–05. Because the Department of Health, Education, and Welfare (“HEW”) (known today as the Department of Health and Human Services) “withdrew the challenged regulations, issued interim regulations complying with the district court’s order, and represented on appeal its intention to issue final compliant regulations . . . the Court of Appeals held that the controversy was mooted by HEW’s actions and remanded the case back to the district court for dismissal.” Kessler, *supra* note 30, at 880.

<sup>51</sup> 42 C.F.R. § 50.209 (2016).

<sup>52</sup> See Corey G. Johnson, *Female Inmates Sterilized in California Prisons Without Approval*, CTR. FOR INVESTIGATIVE REPORTING (July 7, 2013), <http://cironline.org/reports/female-inmates-sterilized-california-prisons-without-approval-4917>.

<sup>53</sup> Only thirty-seven genes, out of more than twenty thousand genes, are found in the mitochondria. Therefore, the baby inherits about 0.2% of its genetic information from the donor parent, resulting

replacement does not really refer to therapy resulting in three parents. In this part, I describe the technology and also the controversy behind the technology.

### *The Science*

Although relatively uncommon, mitochondrial disease can have devastating consequences. Mutated mitochondria can cause a myriad of genetic abnormalities that are passed on through maternal mitochondria.<sup>54</sup> The Food and Drug Administration (FDA) refers mitochondrial replacement, emerging methods of gene altering, as mitochondrial manipulation technologies. The two common methods of such technology utilize the spindle transfer method and the pronuclear transfer method.<sup>55</sup> Under the maternal spindle transfer method, the nuclear DNA is removed from the intended mother's egg, and the rest of the egg with the unhealthy mitochondria is discarded.<sup>56</sup> The nucleus from the donor egg is removed, which leaves healthy mitochondria behind.<sup>57</sup> The intending mother's nucleus is transferred into the donor egg, after the donor egg's nucleus is removed.<sup>58</sup> What results is a healthy egg, which can be fertilized by the father's sperm.<sup>59</sup>

The "three-parent baby" is not new. In the past, scientists have successfully combined the genetic material of three people.<sup>60</sup> In 2001, researchers in New Jersey did so using material from the cytoplasm, the material that surrounds the nucleus of the egg and directs its development after fertilization, from fertile women into the eggs of infertile women.

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in the baby having three genetic parents. Padmini Cheruvu, *Three-Parent IVF and Its Effect on Parental Rights*, 6 HASTINGS SCI. & TECH. L.J. 73, 76 (2014). "It is wrong to say this produces three-parent babies," said Professor Douglas Turnbull, director of the Wellcome Trust Centre for Mitochondrial Research at Newcastle University. Robin McKie, *Families Hope "Frankenstein science" Lobby Will Not Stop Gene Cure for Mitochondrial Disease*, GUARDIAN (Feb. 15, 2014, 7:30 AM), [http://www.theguardian.com/science/2014/feb/15/mitochondrial-disease-gene-cure-ivf?CMP=twf\\_fd](http://www.theguardian.com/science/2014/feb/15/mitochondrial-disease-gene-cure-ivf?CMP=twf_fd). "More than 99.9% of DNA is nuclear DNA and that will not be affected." *Id.*

<sup>54</sup> See Marcy Darnovsky, *Genetically Modified Babies*, N.Y. TIMES (Feb. 23, 2014), [http://www.nytimes.com/2014/02/24/opinion/genetically-modified-babies.html?src=recpb&\\_r=1](http://www.nytimes.com/2014/02/24/opinion/genetically-modified-babies.html?src=recpb&_r=1).

<sup>55</sup> See Cheruvu, *supra* note 53, at 76.

<sup>56</sup> *Id.*

<sup>57</sup> *Id.*

<sup>58</sup> *Id.*

<sup>59</sup> Nita Farahany, *FDA Considers Controversial Fertility Procedure. What's at Stake?*, WASH. POST (Feb. 25, 2014), <http://www.washingtonpost.com/news/voikh-conspiracy/wp/2014/02/25/fda-considers-controversial-fertility-procedure-whats-at-stake/>.

<sup>60</sup> Darnovsky, *supra* note 54.

More than seventeen babies have been born this way in the United States.<sup>61</sup> There were concerns with this practice, which resulted in the FDA barring such research on humans without special permission.<sup>62</sup> Since then, researchers at Oregon Health and Science University have conducted research using the maternal spindle transfer technique on macaque monkeys to great success.<sup>63</sup> Led by reproductive biologist, Shoukhrat Mitalipov, the university has produced five macaque monkeys, four of which are now adults with all five appearing healthy.<sup>64</sup> Mitalipov is now seeking FDA approval to begin human testing in a handful of women who carry defective genes that can lead to these diseases.<sup>65</sup> His research played a large part in spurring the FDA advisory panel to hold a meeting to consider the scientific aspects of mitochondrial manipulation.<sup>66</sup> The FDA held a two-day meeting in 2014 to discuss the scientific aspects of mitochondrial manipulation technologies. The FDA explicitly limited this meeting to a “technical” discussion on the feasibility of safely testing the artificial fertilization technique in humans.<sup>67</sup> Acknowledging the ethical and social policy issues related to genetic modification of eggs and embryos, the FDA staff released a statement declaring such topics as “outside the scope of this meeting.”<sup>68</sup>

The FDA assumed responsibility for the oversight and regulation of human genetic engineering from the Recombinant DNA Advisory Committee (RAC) in 1995.<sup>69</sup> As a result, the FDA’s Center for Biologics Evaluation and Research Advisory Committee for Cellular, Tissue, and Gene Therapies became, and still is, responsible for reviewing and evaluating products associated with gene transfer therapies.<sup>70</sup> In order for the FDA to maintain its control over the review and evaluation of evolving gene transfer therapies, the scope of its jurisdiction was broadened to include semen and other reproductive tissue within the FDA’s regulations

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<sup>61</sup> *Id.*

<sup>62</sup> *Id.*

<sup>63</sup> *Id.*

<sup>64</sup> *Id.*

<sup>65</sup> Karen Weintraub, *FDA Weighs Risks of 3-Person Embryo Fertilization*, USA TODAY (Feb. 24, 2014), <http://www.usatoday.com/story/news/nation/2014/02/24/fda-three-person-embryo-fertilization/5777869/>.

<sup>66</sup> *Id.*

<sup>67</sup> Matthew Perrone, *FDA Mulls Unknowns of Experimental “3-Parent IVF” Embryo Technique*, NBC L.A. (Feb. 25, 2014, 7:12 PM), <http://www.nbclausangeles.com/news/national-international/NATL-FDA-Mulls-Experimental-3-Person-Embryo-IVF-Technique-Genetic-DNA-247181401.html>.

<sup>68</sup> *Id.*

<sup>69</sup> Nicole Baffi, *The Good, the Bad, and the Healthy: How Spindle-Chromosomal Complex Transfer Can Improve the Future*, 74 ALB. L. REV. 361, 369 (2011).

<sup>70</sup> *Id.*

of human cells and tissues.<sup>71</sup> As such, the FDA has jurisdiction over technologies and trials involving maternal spindle transfer because it requires the use of human oocytes, which are reproductive tissues.<sup>72</sup>

Despite the FDA's desires to keep the preliminary meeting restrained to a discussion of the science, more than a half-dozen public speakers urged the FDA to block any human testing of the DNA-swapping technique due to unknown medical, ethical, and societal impacts.<sup>73</sup> The FDA's primary concern in initiating this discussion is safety. There have been successful trials in animals, and the successful creation of healthy human zygotes. The first studies using human eggs showed an increased rate of abnormal fertilization, although zygotes with an appropriate number of pronuclei seemed to develop normally.<sup>74</sup> The discussion from the FDA's panel of genetic experts suggested that further long-term animal trials might be in order before human trials are allowed to begin. The committee chairman said during the Feb. 25<sup>th</sup> meeting that many panelists felt "there was probably not enough data in animals . . . to move on to human trials without answering a few additional questions."<sup>75</sup> As the ramifications of such human testing are far-reaching, the FDA chose a conservative approach and requested further animal testing before green-lighting human trials.

In contrast, regulators in the U.K. did not seem to have the same reservations with moving forward with human trials. The Human Fertilisation and Embryology Authority (HFEA) agency in Britain, which is responsible for oversight of reproductive technologies, conducted an in-depth analysis of mitochondrial transfer and advised the British government to permit mitochondrial transfer "so long as it is safe enough to offer in a treatment setting and is done so within a regulatory framework."<sup>76</sup> They found that the ethical concerns were outweighed by the arguments in favor of permitting mitochondrial replacement, and that it might be unethical to *not* provide parents with the option because of the suffering that this option could mitigate.<sup>77</sup> They recommended that the method be used only in male embryos so the maternal mitochondria was not passed to a future generation. Additionally, the Nuffield Council on Bioethics weighed the issues and determined that given the tremendous

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<sup>71</sup> *Id.*

<sup>72</sup> *Id.*

<sup>73</sup> Perrone, *supra* note 67.

<sup>74</sup> Laura Hercher, *It's a Slippery Slope. Get Over It*, DNA EXCHANGE (Feb. 27, 2014, 10:13 AM), <http://thednaexchange.com/2014/02/27/its-a-slippery-slope-get-over-it/>.

<sup>75</sup> *Id.*

<sup>76</sup> Farahany, *supra* note 59.

<sup>77</sup> *Id.*

individual and social benefits involved, it would be ethical to proceed with these techniques in clinical trials.<sup>78</sup> Most scientists and doctors, particularly those who work with families touched by mitochondrial disease, supported the introduction of the technique.<sup>79</sup>

### *The Controversy*

Those who support mitochondrial replacement argue that the benefits of such procedures far outweigh any ethical concerns. They focus on a quite eugenic reasoning—this is the only way for women with mitochondrial disease to give birth to healthy children to whom they are genetically related.<sup>80</sup> Some even promote their use for age-related infertility. Supporters rebut this claim by pointing out that these new technologies, such as spindle transfer, are developed in the interest of promoting health and welfare—to benefit society—and are distinguishable from the negative form of genetic therapy, eugenics.<sup>81</sup> Professor Nita Farahany of Duke University states that, “Far from opening the floodgates to genetic engineering, mitochondrial transfer offers a limited, safe and ethical alternative to the grave suffering that women with mitochondrial disease would otherwise suffer as they try to have healthy children.”<sup>82</sup> Other supporters argue that the real issues with genetic engineering lie with the limits society set upon such research. Bioethicist Arthur Caplan states that,

how far we go in engineering future generations through genetic manipulations is up to us. We can enact laws and treaties that say yes to gene therapies but no to cosmetic genetic engineering. Holding families hostage by saying they cannot try to repair broken genes to treat diseases because we worry that we cannot put steps or handrails on the slippery slope to designer babies seems wrong to me.<sup>83</sup>

Caplan believes that the line between treatment and enhancement certainly must be drawn now, but that prohibiting such research that would fix diseases would not be the way to prevent any such purported threat of a

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<sup>78</sup> *Id.*

<sup>79</sup> McKie, *supra* note 53.

<sup>80</sup> Darnovsky, *supra* note 54.

<sup>81</sup> Baffi, *supra* note 69.

<sup>82</sup> Weintraub, *supra* note 65.

<sup>83</sup> Arthur Caplan, *Opinion: Three-Parent Babies Are an Ethical Choice*, NBC NEWS (Feb. 26, 2014, 5:06 PM), <http://www.nbcnews.com/health/health-news/opinion-three-parent-babies-are-ethical-choice-n39556>.

eugenics movement.<sup>84</sup> It is very difficult however to draw a principled line between therapy and enhancement.<sup>85</sup> Using the example of vaccinations, one may ask if they are a form of therapy or are they an enhancement of our immune system? The argument can be made for both sides. Some point out that such difficulties when setting a definitive line in the sand regarding therapy vs. enhancement are a common dilemma. There is a need to define the difference between therapy and enhancement.<sup>86</sup>

Critics of these methods say that gene manipulation, in any form, carries with it a great number of risks. Changing the germline of individuals—selecting good genes—has been compared to the eugenics movement.<sup>87</sup> Tabloids tout this as a slippery slope to a “Frankenstein future.”<sup>88</sup> They also worry that there may be risks that blending of mitochondria from one woman with the egg nucleus of another could create serious issues.<sup>89</sup> Both mitochondrial DNA and nuclear DNA change in ways that complement each other. Mixing DNA from different women with a different evolutionary history could be problematic.<sup>90</sup> Because of this, it is unclear whether every mother can “expect a definitely healthy child out of this.”<sup>91</sup> While there may be health benefits of such procedures, many genetic experts had cautioned it could be many years before this process is deemed safe for humans.<sup>92</sup> However, not everyone has heeded the warning. The first seemingly healthy baby born using the mitochondrial replacement method was a true medical tourist, born in Mexico in April 2016 to Jordanian parents with the help of an American fertility specialist.<sup>93</sup> Dr. Zhang, the New York based fertility specialist, has published an initial abstract about this “experiment” of using mitochondrial replacement.<sup>94</sup> This method is not allowed in the United States, which is why the physician

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<sup>84</sup> *Id.*

<sup>85</sup> Patrick Lin, *Therapy and Enhancement: Is There a Moral Difference?*, 29 GENETIC ENGINEERING & BIOTECHNOLOGY NEWS (July 1, 2009), <http://www.genengnews.com/gen-articles/therapy-and-enhancement-is-there-a-moral-difference/2959/?page=2>.

<sup>86</sup> *Id.*

<sup>87</sup> Baffi, *supra* note 69.

<sup>88</sup> McKie, *supra* note 53.

<sup>89</sup> Weintraub, *supra* note 65.

<sup>90</sup> *Id.*

<sup>91</sup> *Id.*

<sup>92</sup> Perrone, *supra* note 67.

<sup>93</sup> Jessica Hamzelou, *Exclusive: World’s First Baby Born With New “3 Parent” Technique*, NEW SCIENTIST (Sept. 27, 2016), <https://www.newscientist.com/article/2107219-exclusive-worlds-first-baby-born-with-new-3-parent-technique/>.

<sup>94</sup> J. Zhang et al., *First Live Birth Using Human Oocytes Reconstituted By Spindle Nuclear Transfer For Mitochondrial DNA Mutation Causing Leigh Syndrome*, 106 FERTILITY & STERILITY, no. 3, 2016, at e375–e376, [http://www.fertstert.org/article/S0015-0282\(16\)62670-5/fulltext?rss=yes](http://www.fertstert.org/article/S0015-0282(16)62670-5/fulltext?rss=yes).

went to Mexico to perform the procedure.<sup>95</sup> Dr. Zhang was quoted in the press as having said Mexico was chosen “because there are no rules there.”<sup>96</sup> Zhang “is adamant that he made the right choice. ‘To save lives is the ethical thing to do, he says.’” Five embryos were processed using mitochondrial replacement and only one developed typically. Tests of various tissue samples from the infant boy born using this method demonstrate that he only has 1.6% of the mother’s mitochondrial DNA. The remainder are from the unaffected donor. The parents were Jordanian Muslims who had already suffered four miscarriages and lost two children to Leigh syndrome. Leigh syndrome is a “fatal disease that involves the gradual deterioration of the nervous system, along with pain, gastric distress and, ultimately, respiratory failure, usually in the first years of life.” The news of an American researcher getting institutional review board approval when this procedure is not allowed in the United States was condemned by many groups. The Center for Genetics and Society called the development “troubling” and the procedure “biologically extreme.”<sup>97</sup>

They urge[d] intended parents who might consider undergoing this biologically extreme procedure to carefully investigate the risks, as well as the areas where evidence of safety is lacking. . . . And we urge scientists and policy makers to condemn rogue experimentation that takes advantage of families’ misplaced trust in people who wear white coats.<sup>98</sup>

Because Zhang’s team avoided destroying embryos, and used a male embryo, which is in line with the UK Protocol, some lauded Zhang’s efforts and deemed him using best practices.<sup>99</sup>

#### *Gene Editing—The Promise, The Science, The Concerns, and the Law*

This subsection provides a general overview of gene editing—the science and the state of the technology at the time of this writing. Some of the techniques that will need to be used in conjunction with human gene editing are not new. In the United States today, artificial insemination and IVF techniques lead to about 100,000 births each year, which is roughly

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<sup>95</sup> *Id.*

<sup>96</sup> Hamzelou, *supra* note 93.

<sup>97</sup> *Id.*

<sup>98</sup> CENTER ON GENETICS AND SOCIETY, Comment On Use Of Mitochondrial Manipulation Techniques By US Scientists In Mexico (Sept. 27, 2016), <http://www.geneticsandsociety.org/article.php?id=9697>.

<sup>99</sup> Hamzelou, *supra* note 93.

2.5% of the 4 million children born annually.<sup>100</sup> Preimplantation genetic diagnosis (PGD) is already being used commonly among those undergoing in vitro fertilization (IVF) to select certain embryos.<sup>101</sup> PGD can be used to select embryos that do not have certain disease-causing mutations or select embryos that are a certain gender.<sup>102</sup> Over the next few decades, many believe that the use of IVF will skyrocket due to developments in bioscience and ultimately make IVF more affordable and easier.<sup>103</sup> Professor Hank Greeley of Stanford University recently wrote a book, provocatively entitled *The End of Sex*.<sup>104</sup> In this book, Professor Greeley describes his vision of how gene editing will be used in conjunction with pre-implantation genetic diagnosis (PGD) in what he labels “Easy PGD.”<sup>105</sup> Greeley predicts that much like whole genome sequencing that cost \$50 million a decade ago and now costs \$1,500, Easy PGD will also be cheap in the future.<sup>106</sup> Depending on one’s perspective, Greeley paints a dystopian or utopian vision where parents-and insurers and government health programs-can save on care of sick children by using Easy PGD to avoid such births.<sup>107</sup> This section describes the science behind gene editing briefly to explain how it could potentially revolutionize reproduction.

### *The Science*

After the United States successfully sequenced the full human genome as part of the Human Genome Project, there was much hope that therapies and techniques for diagnosing and treating diseases would be created.

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<sup>100</sup> Henry T. Greeley, *In 20 to 40 Years, Most Americans Won’t Have Sex to Reproduce. Get Ready.*, VOX (Sept. 16, 2016, 9:20 AM), <http://www.vox.com/2016/9/16/12931962/future-sex-reproductive-technology-ethics-ivf> [hereinafter *In 20 to 40 Years*].

<sup>101</sup> Erika Check Hayden, *Should You Edit Your Children’s Genes?*, NATURE (Feb. 23, 2016), <http://www.nature.com/news/should-you-edit-your-children-s-genes-1.19432>.

<sup>102</sup> *Id.*

<sup>103</sup> *In 20 to 40 Years*, *supra* note 100.

<sup>104</sup> HENRY T. GREELEY, *THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION* 1–3 (2016) [hereinafter *THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION*].

<sup>105</sup> *Id.* In both his book and an online article about this topic, Greeley theorizes that one day in the near future induced pluripotent stem cells (iPSCs) which are skin cells made to become like embryonic stem cells that could be turned into gametes to carry a prospective parent’s own genetic variations. *In 20 to 40 Years*, *supra* note 100. In this version of gene editing, eggs would not be required. *Id.* This makes it “easy.” A female would provide a small skin sample and the male the sperm, and the skin cells would be turned into mature eggs to be fertilized. *Id.* The iPSC process, if plausible, would be appealing for lesbian couples looking to have a clinic make both eggs and sperm out of one of the partner’s skin and then transplanted in the other partner’s womb. *Id.* For the purposes of this Article, I am focusing on the types of gene editing that are currently being used by researchers.

<sup>106</sup> *THE END OF SEX AND THE FUTURE OF HUMAN REPRODUCTION*, *supra* note at 104.

<sup>107</sup> *Id.*



Clustered regularly interspaced short palindromic repeats (CRISPR) are segments of DNA (usually bacterial DNA).<sup>108</sup> CRISPR is so sensitive that scientists can use it to explore the billions of chemical combinations that make up code of the DNA in a cell, and to make a single key change.<sup>109</sup> Best of all, it is fast and cheap and seems to be accelerating all kinds of research.<sup>110</sup> For example, one form of CRISPR was used to help reverse cancer in an infant suffering from an aggressive form of leukemia—she remains the first person to date whose life has been saved by gene editing.<sup>111</sup>

In particular, CRISPR/Cas9 allows researchers to “modify the genetic makeup of living organisms, including humans.”<sup>112</sup> Cellular apoptosis susceptibility (Cas) proteins are enzymes that act as a nuclease. Thus, the Cas proteins function to cut in or cut out pieces of DNA.<sup>113</sup> CRISPR sequences and Cas proteins work together to identify and edit genetic sequences.<sup>114</sup> CRISPR-Cas immunity is a natural process that occurs within bacteria and archaea, primitive, but still living bacterial ancestors.<sup>115</sup> Thus, although the CRISPR/Cas9 system is referred to as a new type of biotechnology, humans actually did not invent it. CRISPRs are naturally occurring sequences of DNA commonly found in most prokaryotes, the zoological family that includes bacteria.<sup>116</sup> The significance of CRISPRs is that once scientists discover CRISPR sequences within a genome, they can use it as a landmark for identifying the surrounding genetic code.<sup>117</sup> Cas proteins, also naturally occurring and necessary for life, can cleave the DNA near the CRISPR sequence and insert new genetic material at this location.<sup>118</sup> Researchers use the CRISPR/Cas9 technology to ultimately change DNA sequences by “introducing or correcting genetic mutations—

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<sup>108</sup> Carl Zimmer, *Breakthrough DNA Editor Born of Bacteria*, QUANTA (Feb. 6, 2015), <https://www.quantamagazine.org/20150206-crispr-dna-editor-bacteria/>.

<sup>109</sup> Fergus Walsh, *Gene Editing Technique Could Transform Future*, BBC NEWS (June 6, 2016), <http://www.bbc.com/news/health-36439260>.

<sup>110</sup> *Id.*

<sup>111</sup> *Id.*

<sup>112</sup> *The Science and Ethics of Genetically Engineered Human DNA: Hearing Before the Subcommittee on Research & Technology Committee on Science, Space, and Technology House of Representatives*, 114th Cong. 114—24 (2015) (statement of Dr. Victor J. Dzau, President, Institute of Medicine, The National Academy of Sciences).

<sup>113</sup> *Id.*

<sup>114</sup> *Id.*

<sup>115</sup> David Cyranoski & Sara Reardon, *Chinese Scientists Genetically Modify Human Embryos*, NATURE (Apr. 22, 2015), <http://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378>.

<sup>116</sup> *Id.*

<sup>117</sup> *Id.*

<sup>118</sup> *Id.*

in a wide variety of cells and organisms.”<sup>119</sup> This technology also has the potential to make permanent modifications to human DNA in an egg, sperm, or human embryos. These modifications will potentially be passed down to succeeding generation. Thus, this type of gene editing is referred to as germline editing.<sup>120</sup> According to Doudna, one of the creators of the technology<sup>121</sup> by using the CRISPR/Cas9 technology, they are “basically able to have a molecular scalpel for genomes.”<sup>122</sup> The reason that germline editing is so controversial is that CRISPR/Cas9 technology can alter the genetic material of a person and also pass that DNA being passed on. Thus, it may remove both “bad” and “good” genetic codes as well.<sup>123</sup>

There are many potential uses for CRISPR/Cas9 technology, but for the purposes of this article, human germline gene editing is most relevant. The development of this gene editing technology could potentially lead to the cure for diseases such as Huntington’s Disease, sickle cell anemia, a variety of other illnesses. At the time of this writing, CRISPR/Cas9 has not reached the level of accuracy needed to allow germline editing. For example, the Chinese scientists that used this technology to alter human embryos only successfully introduced the DNA they wanted to in a fraction of the twenty-eight embryos that had been successfully sliced.<sup>124</sup>

The next part provides an overview of the concern about such gene editing, relevant international and national laws, and the state of the technology at this point. Because there is so much research in this area, this overview provides a snapshot of what has been reported about this technology to date. Perhaps by the time this article is published even more examples of human gene editing will come to light.

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<sup>119</sup> *The Science and Ethics of Genetically Engineered Human DNA: Hearing Before the Subcommittee on Research & Technology Committee on Science, Space, and Technology House of Representatives*, 114th Cong. 114–24 (2015) (statement of Dr. Doudna).

<sup>120</sup> *Id.*

<sup>121</sup> There is a patent dispute about who created CRISPR/Cas9 that is outside the scope of this Article.

<sup>122</sup> Kevin Loria, *The Researchers Behind “The Biggest Biotech Discovery of the Century” Found it by Accident*, BUS. INSIDER, (July 7, 2015, 2:14 PM), <http://www.businessinsider.com/the-people-who-discovered-the-most-powerful-genetic-engineering-tool-we-know-found-it-by-accident-2015-6>.

<sup>123</sup> Kevin Loria, *Chinese Scientists Just Admitted to Tweaking the Genes of Human Embryos for the First Time in History*, BUS. INSIDER (Apr. 22, 2015, 4:53 PM), <http://www.businessinsider.com/chinese-scientists-genetic-modification-human-embryo-crispr-2015-4>.

<sup>124</sup> *Id.*

*Human Germline Gene Editing: The Early Outlaws*

In 2015, using CRISPR/Cas9 technology, Chinese scientists reported successfully editing the human genome.<sup>125</sup> Chinese scientists used human embryos that contained a gene mutation and edited out the genetic mutation that causes  $\beta$ -thalassemia, a potentially fatal blood disorder.<sup>126</sup> The experiment did not work perfectly, but a very low percentage of embryos actually received the correct substitution. This research sparked a national and international conversation about human germline gene editing and how to address it. Many scientists felt that the technology was too early to test on human embryos.<sup>127</sup> This led to an International Summit on Human Gene Editing in Washington, D.C., which concluded that it was far too early to try to create babies from embryos that had their genes edited.<sup>128</sup> However, it left open the possibility that research on human embryos itself may be “acceptable”<sup>129</sup> by allowing and encouraging “intensive basic research” to explore the safety and potential benefits of human gene editing.<sup>130</sup>

As of the time of this writing, stem-cell biologist, Fredrik Lanner, is the first researcher to attempt to modify the genes of healthy human embryos.<sup>131</sup> The purpose behind Lanner’s research in editing the embryos is to gain knowledge about how genes regulate early embryonic development—which could potentially lead to new ways to treat infertility and prevent miscarriages.<sup>132</sup> Such research could also be used down the road to learn more about embryonic stem cells, by studying how they are regulated in the actual embryo, in hopes of being able to treat other diseases

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<sup>125</sup> Cyranoski & Reardon, *supra* note 115.

<sup>126</sup> *Id.*

<sup>127</sup> Edward Lanphier et al., *Don’t Edit the Human Germ Line*, 519 NATURE 410, 410–11 (Mar. 12, 2015), <http://www.nature.com/news/don-t-edit-the-human-germ-line-1.17111>. In this critique, Lanphier notes that “We are not making a comparison between the replacement of faulty mitochondrial DNA in an egg or embryo with healthy DNA from a female donor and the use of genome-editing in human embryos. In mitochondrial transfer, the aim is to prevent life-threatening diseases by replacing a known and tiny fraction of the overall genome.” *Id.* However, in terms of eugenic focus of this Article, both mitochondrial DNA transfer and gene editing pose issues of fixing and improving social stock.

<sup>128</sup> Rob Stein, *Breaking Taboo, Swedish Scientist Seeks to Edit DNA of Healthy Human Embryos*, NPR (Sept. 22, 2016, 5:07 AM), <http://www.npr.org/sections/health-shots/2016/09/22/494591738/breaking-taboo-swedish-scientist-seeks-to-edit-dna-of-healthy-human-embryos> [hereinafter *Breaking Taboo*].

<sup>129</sup> *Id.*

<sup>130</sup> Rob Stein, *Scientists Debate How Far to Go in Editing Human Genes*, NPR (Dec. 3, 2015, 4:39 PM), <http://www.npr.org/sections/health-shots/2015/12/03/458212497/scientists-debate-how-far-to-go-in-editing-human-genes> [hereinafter *Scientists Debate*].

<sup>131</sup> *Breaking Taboo*, *supra* note 128.

<sup>132</sup> *Id.*

such as diabetes or Parkinson.<sup>133</sup> Lanner first used four embryos that were donated by couples who had gone through the IVF process in his research.<sup>134</sup> Currently, Lanner is only studying the modified embryos for the first seven days of their growth and not allowing them to develop past fourteen days, to steer clear of the fourteen day rule.<sup>135</sup> Lanner's research is permitted by Swedish law, which allows for embryonic studies to occur for up to fourteen days after fertilization.<sup>136</sup> The embryos must then be destroyed.<sup>137</sup>

### *The Concerns and Rules*

In this Article, I focus on how these new advances in technology are making eugenics acceptable, by focusing on producing healthy, non-diseased babies. The scientists that are concerned about CRISPR/Cas9 are not focused on that critique for the most part. Of course, there are some voices in the conversation, such as Marcy Darnovsky of the Center for Genetics and Society, who believe that altering the human germline in embryos for clinical purposes is a line that should not be crossed.<sup>138</sup> There is a slippery slope concern about how opening the door to genetically modified embryos that are disease free could one day lead to creating “designer” babies who are healthier, smarter, and taller.<sup>139</sup> This is an eugenic concern because such babies could be perceived as being “biologically superior” and lead to social issues.<sup>140</sup> Hank Greeley dismisses such concerns in his book because he believes that the technology does not lead to enough advantages to truly create superior babies. Although he may be right, when coupled with the other advantages these babies are likely to have, it is a significant advantage. What I mean is that those created with gene editing technology will not only be genetically superior, but they will have wealthier parents (who can afford the technology) and likely be white (most users of ART are white and upper middle class and there is no reason

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<sup>133</sup> *Id.*

<sup>134</sup> *Id.*

<sup>135</sup> *Id.*

<sup>136</sup> EUROSTEMCELL, <http://www.eurostemcell.org/regulations/regulation-stem-cell-research-sweden> (last updated Mar. 1, 2012).

<sup>137</sup> *Id.*

<sup>138</sup> Francis S. Collins, *Statement on NIH Funding of Research Using Gene editing Technologies in Human Embryos*, NAT. INST. HEALTH (Apr. 28, 2015), <https://www.nih.gov/about-nih/who-we-are/nih-director/statements/statement-nih-funding-research-using-gene-editing-technologies-human-embryos>.

<sup>139</sup> *Scientists Debate*, *supra* note 130.

<sup>140</sup> *Breaking Taboo*, *supra* note 128.

to think that this profile would change for utilizers of gene editing for health or social purposes). By that reasoning, minorities and the poor will likely face the double or triple bind of being of a minority background, having poorer educational and other opportunities due to their financial status, and having just ordinary—or worse—diseased genes. There is a valid concern that this could lead to genetic discrimination.<sup>141</sup> In the disability-rights community, the saying “nothing about us without us” reflects how the disabled community feels left out of this debate.<sup>142</sup> They argue that scientists, policymakers and bioethicists should take steps to ensure that this community is essentially not edited out.<sup>143</sup>

In the United States, there are legislative and regulatory prohibitions against gene editing of human embryos.<sup>144</sup> There are forty countries that have prohibited the editing of embryos by law.<sup>145</sup> Additionally, twenty-one countries, not including the United States, have signed the Council of Europe treaty which prohibits editing embryos.<sup>146</sup> Internationally, China, India, Ireland, and Japan forbid germline editing gene modification in general.<sup>147</sup> It is not clear that the United States would ever ban gene editing completely, even though a recent Pew Research Poll found that 68% of Americans are “very” or “somewhat” concerned with the implications of gene editing.<sup>148</sup> Currently, the FDA, NSF, NIH, and NIST are all in the process of forming scientific standards for a future generation of sequencing.<sup>149</sup> Currently, the United States has put in place legislative prohibitions that do not allow the use of federal funds for any research that involves human embryos when there is oversight by the U.S. Food and Drug Administration or other government agencies. The NIH will not fund any use of gene editing technologies in human embryos.<sup>150</sup> The main

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<sup>141</sup> Walsh, *supra* note 109.

<sup>142</sup> Hayden, *supra* note 101.

<sup>143</sup> *Id.*

<sup>144</sup> Collins, *supra* note 138.

<sup>145</sup> Anna Zaret, *Editing Embryos: Considering Restrictions on Genetically Engineering Humans*, 67 HASTINGS L.J. 1805, 1811 (2016).

<sup>146</sup> *Id.*

<sup>147</sup> Motoko Araki & Tetsuya Ishli, *International Regulation Landscape and Integration of Corrective Genome Editing into In Vitro Fertilization*, BIOMED CENTRAL (Nov. 24, 2014), <http://rbej.biomedcentral.com/articles/10.1186/1477-7827-12-108#MOESM1>.

<sup>148</sup> Ben Adams, *U.S. Wary on Biotech Advances; Gene Editing, CRISPR 'Raising Urgency'*RU, FIERCEBIOTECH (July 27, 2016, 4:22 AM), <http://www.fiercebiotech.com/biotech/u-s-wary-biotech-advances-gene-editing-crispr-raising-urgency-debate>.

<sup>149</sup> *Unlocking the Cures for America's Most Deadly Diseases: Hearing Before the Subcommittee on Space, Science, and Competitiveness of the Committee on Commerce, Science, and Transportation*, 114th Cong. 30 (2015) (statement of Dr. Keith R. Yamamoto, Vice Chancellor of Research, University of California).

<sup>150</sup> Collins, *supra* note 138.

concerns are safety issues, ethical issues regarding altering the germline in a way that affects the next generation without their consent, and the lack of compelling medical applications justifying the use of such gene editing techniques.<sup>151</sup> However, this type of research does not have constraints when the work is completed internationally, not using federal funding.<sup>152</sup>

### III. POLITICALLY CORRECT EUGENICS

This Section connects how the new technologies discussed in the last Section actually open the doors to a new, acceptable, and palatable eugenics. Of course, eugenic beliefs are not called eugenics anymore. Due to the stigma of the term eugenics, no one would actually self-identify as holding eugenic beliefs. The more politically correct way of phrasing eugenic ideals is focusing on health. The ideas that one would like to have a healthy baby and live a long and healthy life go without saying. Much research is being done to try to understand and prevent diseases that occur at the end of life such as cancer, heart disease, and Alzheimer's. Evans and Moreno have argued that the new focus on genetic ailments and cures and identification is similar to old eugenic beliefs.<sup>153</sup> Just as eugenics had a heritable component, we now focus on genetics and what traits one may pass on.<sup>154</sup> Today, individuals themselves collect data via genetic testing through physicians or over the counter like 23andme, similar to as eugenicists who used to map "family trees."<sup>155</sup> Unlike eugenics, which was based on bad science in many respects such as using craniometers to measure intelligence, the new politically correct eugenics uses "good science"—cutting edge techniques that prevent diseased children from being born. I focus on the goal to have a healthy child—and how that may look different in a few years than it does even today due to gene editing and other advances. In this section, I discuss how many times, the purpose of current prenatal testing after pregnancy and pre-implantation genetic diagnosis share common goals with the earlier eugenic ideals. I do not mean this as a critique of these types of testing or techniques, but to demonstrate that we already have a sort of politically correct eugenics

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<sup>151</sup> *Id.*

<sup>152</sup> *The Science and Ethics of Genetically Engineered Human DNA: Hearing Before the Subcommittee on Research & Technology Committee on Science, Space, and Technology House of Representatives*, 114th Cong. 114–24 (2015) (statement testimony of Dr. Victor J. Dzau, President, Institute of Medicine, The National Academy of Sciences).

<sup>153</sup> Evans & Moreno, *supra* note 8, at 287.

<sup>154</sup> *Id.*

<sup>155</sup> *Id.*

currently—even without considering the technologies of gene editing or mitochondrial nuclear transfer. Technology moves quickly, and our society adapts quickly to such advances, even before we can carefully consider the legal and ethical ramifications of such technology. I suggest that gene editing and new advances will likely significantly alter the way many people have children, all in the name of good health. Examining these possibilities using reproductive justice and disability justice frames are particularly relevant because there is a real concern that poor minority women will be ones who will be left out of this “genetic revolution.” This will be due to lack of access to such technology due to cost and warranted lack of trust in the medical system due to the history described earlier. The fact that minorities may not be the beneficiaries of this technology is not just worthy of a footnote or a side discussion—it is a central concern. Given how eugenics served to diminish minority populations, this needs to be a major consideration in how this technology is used and disseminated. In much of what is written about gene editing and even in the International Summit and subsequent meetings, reproductive and disability justice has not been focused upon enough. This is not a question of whether to allow the technology or not. Gene editing in humans and mitochondrial replacement is going to happen, and it will become more accurate and accessible. Even if the United States decides (which is unlikely) to ban either of these technologies, as I noted above, there will be countries without rules against these advances. Wealthy people in the United States who are worried about avoiding a heritable disease in their family, who can afford to travel elsewhere, will thus have access to the technology. Banning such technology in the United States would actually serve to increase the cost and decrease access to such technology. Daniel Kevles, of New York University, wrote a commissioned paper for the International Summit on Human Gene Editing in Washington, D.C., entitled “The History of Eugenics.”<sup>156</sup> In his paper, Kevles notes that unlike the eugenics of the past, where governments played a role, the eugenics of the future will likely be a result of consumer choice—people will be requesting gene editing. The fact that gene editing or similar technology is available is in itself a value statement—that it is worthwhile at best, or not illegal or offensive at worst. Even if the United States decides to take a slower approach to these technologies, much like other reproductive technology, we can expect people who can afford to—going off shore to take a chance at gene editing.

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<sup>156</sup> Kevles, *supra* note 2.

*Prenatal Genetic Testing*

The idea that one would like to have a healthy baby and live a long and healthy life often go without saying. If a pregnant woman currently does not get prenatal care, or worse drinks or uses drugs during pregnancy, societal response is harsh.<sup>157</sup> Expectant mothers are supposed to protect the health of the fetus they are carrying, and can face criminal penalties if they do not. When a pregnant woman does receive prenatal care, there is a wide variety of prenatal testing that may be offered to her, particularly if she has any risk factors such as advanced maternal age. In the past, such testing involved amniocentesis or chorionic villi sampling, which were invasive, painful, and could risk the pregnancy itself. Today, noninvasive prenatal testing (“NIPT”) is widely available early in pregnancy. Often with a simple blood test, a woman can find out much about her fetus—including its gender and potential genetic predispositions. A woman who chooses such testing is not thought of as a eugenicist, even if she is undergoing such testing with the thought that she may terminate a pregnancy if the fetus carries a serious genetic ailment.<sup>158</sup> The goal of having a healthy baby is broadly embraced. In the United States today, undergoing NIPT is not the standard of care for all women. NIPT is not error proof or as accurate as other diagnostics tests. As of now, the American College of Obstetrics and Gynecology (“ACOG”) only recommends caution when using such testing.<sup>159</sup> Such testing is “optional” today, but more and more women request such testing. Depending upon future ACOG guidance, such testing may be covered by insurance. Under the Affordable Care Act, pregnancy care is an essential benefit offered to those under an expanded Medicaid program in many states and to those covered by large employer sponsored health insurance. More information is seen as empowering, instead of oppressive. This is quite a different scenario than a physician or state strong arming women into sterilization. Here, women are proactively seeking more information to make an educated decision about their pregnancy. If a woman undergoes testing that identifies a certain genetic anomaly through noninvasive prenatal testing, and it is confirmed by a

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<sup>157</sup> See Seema Mohapatra, *Unshackling Addiction: A Public Health Approach to Drug Use During Pregnancy*, 26 WIS. J.L. GENDER & SOC’Y 241, 244 (2011) (noting that a punitive approach to drug use during pregnancy is counterproductive and arguing for a public health approach).

<sup>158</sup> Due to the false positives in NIPT, a diagnostic test such as an amniocentesis is needed to diagnose a genetic ailment, even after a positive NIPT. *M. Cell-free DNA Screening for Fetal Aneuploidy*, Comm. Op. No. 640, AM. C. OBSTETRICIANS GYNECOLOGISTS 4–5 M. (2015), <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Genetics/co640.pdf?dmc=1&ts=20161016T1147062952>.

<sup>159</sup> See *id.*



diagnostic test, the woman is faced with a choice—carry the pregnancy to term and raise a child with that condition or if it is early enough in the pregnancy, terminate the pregnancy. In the case of testing that reveals that a child will be born with Down Syndrome, a non-fatal disease, reports show that the vast majority of those who receive a positive diagnosis abort the fetus.<sup>160</sup>

The next section examines the new politically correct eugenics that may result from these new technologies through the lenses of disability justice and reproductive justice. Examining this issue through these perspectives helps put the focus on voices and segments of the population that are often missing in this debate.

There is a legitimate worry that the availability of gene editing more widely will result in the promotion of a health ableism.<sup>161</sup> Ableism is defined as “discrimination in favor of able-bodied people.”<sup>162</sup> The term also extends beyond overt discriminatory acts (intentional or not) to include the way our culture views disabled people in theory.<sup>163</sup> Ableism contributes to the beliefs that people with disabilities need to somehow be fixed, cannot function as full members of society, and that having a disability is a defect rather than a dimension of difference.<sup>164</sup> By viewing those with disabilities as being “defective,” those with disabilities are often marginalized, discriminated against, and devalued in this society.<sup>165</sup> Imagine a society where gene editing and mitochondrial transfer take hold, and people who can afford these technologies take advantage of these technologies to avoid having children with disabilities. Those families who choose not to use such technology for moral, religious, or economic reasons may be subject to scrutiny. As this technology becomes cheaper, health insurers may try to nudge people who have family histories of diseases that cost insurers a lot of money to try to avoid having babies with such ailments, whether via NIPT, gene editing or whatever the latest technology may end up being.

Gene editing and new advances will likely significantly alter the way many people have children, all in the name of good health. Examining these possibilities using reproductive justice and disability justice frames are particularly relevant because there is a real concern that poor minority

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<sup>160</sup> See Alicia Ouellette, *Selection Against Disability: Abortion, ART, and Access*, 43 J.L. MED. ETHICS 211, 212 (2015).

<sup>161</sup> Evans & Moreno, *supra* note 8, at 289.

<sup>162</sup> Julie Zeilinger, *6 Forms of Ableism We Need to Retire Immediately*, MICMIC (Jul. 7, 2015), <https://mic.com/articles/121653/6-forms-of-ableism-we-need-to-retire-immediately#.vRwu16dDw>.

<sup>163</sup> *Id.*

<sup>164</sup> *Id.*

<sup>165</sup> *Id.*

women will be ones who will left out of this “genetic revolution.” This will be due to lack of access to such technology because of both cost and warranted lack of trust in the medical system due to the history described earlier. The fact that minorities may not be the beneficiaries of this technology is not just worthy of a footnote or a side discussion—it is a central concern. Given how eugenics served to diminish minority populations, this needs to be a major consideration in how this technology is used and disseminated. In much of what is written about gene editing and even in the International Summit and subsequent meetings, reproductive and disability justice has not been focused upon enough. This is not a question of whether to allow the technology or not. Gene editing in humans and mitochondrial replacement is going to happen, and it will become more accurate and accessible. Even if the United States decides (which is unlikely) to ban either of these technologies, as I noted above, there will be countries without rules against these advances. Wealthy people in the United States who are worried about avoiding a heritable disease in their family, who can afford to travel elsewhere, will thus have access to the technology. Banning such technology in the United States would actually serve to increase the cost and decrease access to such technology. Daniel Kevles, of New York University, wrote a commissioned paper for the International Summit on Human Gene Editing in Washington, D.C. entitled “The History of Eugenics.”<sup>166</sup> In his paper, Kevles notes that unlike the eugenics of the past, where governments played a role, the eugenics of the future will likely be a result of consumer choice—people will be requesting gene editing.<sup>167</sup> The fact that gene editing or similar technology is available is in itself a value statement—that it is worthwhile at best, or not illegal or offensive at worst. Even if the United States decides to take a slower approach to these technologies, much like other reproductive technology, we can expect people who can afford to—going off shore to take a chance at gene editing.

#### IV. EXAMINING THESE ISSUES USING DISABILITY JUSTICE AND REPRODUCTIVE JUSTICE

##### *Disability Justice*

Although we are possibly decades away from the science of using gene editing to “enhance” human embryos, gene editing and mitochondrial

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<sup>166</sup> Kevles, *supra* note 2.

<sup>167</sup> *Id.*

replacement open the door to such enhancement. This is all done in the name of health. If as a parent, one provides a child with—the best schools and opportunities—it is logical that a parent may wish to provide their children with a better genetic chance for success and against future

disabilities by utilizing these technologies. Although this is done with the best of intentions, it will have the effect of lessening the worth of lives with those with disabilities. As Ruha Benjamin points out, “Many practices that were optional yesterday are medicalized today. Likewise, traits and behaviors that we may regard as “enhancement” today may very well find a therapeutic justification tomorrow.”<sup>168</sup> Benjamin notes that even the term “gene editing” carries with it a sanitized implication of removing something that should not be there.<sup>169</sup> She suggests that shredding rather than editing may be closer to the truth for disabled people.<sup>170</sup>

To understand the disability justice frame, it is helpful to briefly examine where it grew from—the disability rights movement. The disability rights movement incorporates the belief that people with disabilities share a common experience of systematic exclusion, and that their “disability” depends crucially on the social practices that create that shared experience.<sup>171</sup> To most disability rights advocates, “disability” is not an inherent trait of the “disabled” person; rather, it is a condition that results from the interaction between some physical or mental characteristic labeled an “impairment” and the contingent decisions that have made physical and social structures inaccessible to people with that condition.<sup>172</sup> The movement believes the proper remedy for disability-based disadvantage is the need for civil rights legislation to eliminate the attitudes and practices that exclude people with actual, past, or perceived impairments from opportunities to participate in public and private life.<sup>173</sup>

The disability rights movement arose in the 1970s as a response to this country’s then-prevalent approach to disability, which focused on medical treatment, physical rehabilitation, charity, and public assistance.<sup>174</sup> Virtually the entire ideology of the modern disability rights movement can be seen as

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<sup>168</sup> Ruha Benjamin, *Interrogating Equity: A Disability Justice Approach to Genetic Engineering*, ISSUES IN SCI. & TECH., Volume XXXII Issue 3, Spring 2016, <http://issues.org/32-3/interrogating-equity-a-disability-justice-approach-to-genetic-engineering/>.

<sup>169</sup> *Id.*

<sup>170</sup> *Id.*

<sup>171</sup> Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 VA. L. REV. 397, 426 (2000).

<sup>172</sup> *Id.*

<sup>173</sup> *Id.*

<sup>174</sup> *Id.* at 427.

a reaction to that “medical/pathological paradigm” of disability.<sup>175</sup> Activists with disabilities believed the dominant approach inappropriate because it treated disability as an inherent personal characteristic that should ideally be fixed, rather than as a characteristic that draws its meaning from social context.<sup>176</sup> Where disability is treated as a medical condition or functional deficit, it is readily seen as a “personal tragedy”—“some terrible chance event which occurs at random to unfortunate individuals.”<sup>177</sup> Such a view encourages dependence on doctors, rehabilitation professionals, and charity.<sup>178</sup> It also stigmatizes people with disabilities, by defining them as something less than normal, and directs them into confining social roles in which they can enter society only “on the terms of the able-bodied majority.”<sup>179</sup> The reality is that disability is very common, especially due to ageing. “One in five people in the United States is living with some type of physical, intellectual, developmental or psychiatric disability.”<sup>180</sup> Thus, people with disabilities constitute one of the largest minority groups in the United States.<sup>181</sup> According to the 2010 U.S. Census, more than 57 million people live with disabilities.<sup>182</sup> “Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes.”<sup>183</sup> The disability rights movement is widely credited with helping passage of the Americans with Disabilities Act.<sup>184</sup> Disability rights focuses on a social model of disability, rather than a medical model of disability, which focuses on cures or prevention. The social model of disability acknowledges that disability is “not inherently harmful, negative, deviant, or defective.”<sup>185</sup> While the medical model dictates that the problem lies in the individual, the social model of disability pinpoints the problem in society’s inability to accept and accommodate disability. In the social model of disability, a disability is not a medical problem that requires

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<sup>175</sup> *Id.*

<sup>176</sup> *Id.*

<sup>177</sup> Bagenstos, *supra* note 171, at 427.

<sup>178</sup> *Id.*

<sup>179</sup> *Id.* at 476.

<sup>180</sup> *The Fight for Civil Rights for People with Disabilities*, DISABILITY JUST., <http://disabilityjustice.org>.

<sup>181</sup> *Id.*

<sup>182</sup> *Id.*

<sup>183</sup> *Disability and Health*, WORLD HEALTH ORG., <http://www.who.int/mediacentre/factsheets/fs352/en/> (last updated Nov. 2016).

<sup>184</sup> *Id.*

<sup>185</sup> *Generations Ahead: A Disability Rights Analysis Of Genetic Technologies*, GENERATIONS AHEAD, 5, <http://www.generations-ahead.org/files-for-download/articles/GenerationsAheadDisabilityRightsConveningReport.pdf>.

fixing, but rather a social problem.<sup>186</sup> If society were to change prevailing views on disability, make the environment accessible to all, and find effective ways to more fully integrate people with disabilities into society, then disability would simply be another way of living.<sup>187</sup>

Disability justice aims to expand from the individual rights framework to highlight the impact of disability on certain populations, especially the poor, people of color, and women.<sup>188</sup> Disability rights and disability justice are not necessarily mutually exclusive.<sup>189</sup> Rather, disability justice examines how disability operates in tandem with class, race, and sexuality.<sup>190</sup> When examining gene editing and mitochondrial transfer through the disability justice frame, one would want to explore how people of color may view these scientific technologies based upon the history of medical experimentation discussed before. It is important to get these communities involved in the debate and get their input, advocacy, and perspective. There are serious issues of fairness and equity that must be debated within the disabled community. There is a possibility that some would want access to these technologies, but could not afford it. Poor people, who may not even be able to afford health care, are certainly not going to be able to access this technology. When these technologies are in the experimental stages, it is also important that diverse people are included for the most accurate results. These underrepresented communities need to have a part in the research and policy-making.

### *Reproductive Justice*

In addition to disability justice, a reproductive justice analysis of gene editing and mitochondrial transfer is helpful to emphasize the need to include diverse communities in the policy making process when deciding on how these technologies should be used. Reproductive justice is a movement that has been led by women of color involved in social justice and women's health care movements.<sup>191</sup> The crux of a reproductive justice analysis is to examine the social context in which reproductive health decisions are made.<sup>192</sup> Trying to improve the species by "fixing" genes is

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<sup>186</sup> *Id.*

<sup>187</sup> *Id.*

<sup>188</sup> *Id.* at 13.

<sup>189</sup> *Id.*

<sup>190</sup> *Id.*

<sup>191</sup> *Reproductive Justice Briefing Book: A Primer on Reproductive Justice and Social Change*, PROTECTIVE CHOICE, <http://www.protectchoice.org/downloads/Reproductive%20Justice%20Book.pdf>.

<sup>192</sup> *Id.*

reminiscent of eugenic beliefs, and this will be more troublesome for Blacks who are familiar with the recent history of eugenics in the United States. Even though much of the public may be in favor of genetic enhancement,<sup>193</sup> marginalized communities may become even more disadvantaged with their use. This debate is not new, but the technology is being developed and ready for use much faster than the consequences are being analyzed. Reproductive justice requires us to look beyond those who can afford and choose to use the technology to have a more perfect or healthy child, and examine how it affects those of us who do not wish to or cannot afford it. Reproductive justice should ensure that those who have children with special needs are taken care of, and that insurers cannot coerce individuals to use technology that they may not morally believe in or via a medical system that they may not trust. Women, who have children with traits or diseases that could have been edited, or who do not wish to have the interference of these technologies, may face great pressure to use them, especially if powerful forces such as insurers and the government are encouraging such use. The lens of reproductive justice allows us to examine how assumptions about disability may affect the use and access to these technologies.<sup>194</sup>

Kimberly Mutcherson has noted that the backbone of reproductive justice is its commitment to intersectionality<sup>195</sup>—meaning it is important to analyze how the reproductive decisions affect women of specific races, ability, and classes. Throughout this article, I have noted how what may seem like win-win technologies would not necessarily be seen that way from the perspective of some Black, disabled, and poor women. Reproductive justice requires that we consider and include these points of views.

Additionally, as opposed to reproductive rights, which focused only on the right to choose an abortion, reproductive justice also focuses on the right to have a child. In the context of gene editing, reproductive justice requires that a woman who chooses not to utilize such technologies will be able to do so, without financial, social, or personal penalties imposed. By allowing these technologies, society is making a statement that certain types of genes should be fixed. This has an impact on those who are not “fixed” and who have children who suffer from these commonly edited ailments.

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<sup>193</sup> Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKELEY TECH. L.J. 897, 935 (2007).

<sup>194</sup> Zakiya Luna & Kristin Luker, *Reproductive Justice*, 9 ANN. REV. L. & SOC. SCI. 327, 328 (2013).

<sup>195</sup> Kimberly M. Mutcherson, *Procreative Pluralism*, 30 BERKELEY J. GENDER L. & JUST. 22, 43 (2015).

Legal protections may need to be in place to ensure that both the positive and negative rights are protected in this context.

Allowing these technologies to be privately available privileges those who can afford these technologies while potential disadvantaging those who cannot. This is a similar form of stratified reproduction that Mutcherson discusses in the assisted reproduction context.<sup>196</sup> Financial assistance from the government for the use of these technologies may help certain populations by improving access, but that may at the same time, further devalue the disabled community. This tension is real and can only be properly explored by inclusion of these diverse voices in the debate over the use of this technology. Additionally, there may be a fear that if there is greater financial assistance with gene editing and mitochondrial transfer, this may have a coercive effect. As I have described earlier, the eugenic history of the United States may be a reason to be concerned about state intervention in this context. If that is so, this may develop as a private form of eugenics. Disability and reproductive justice require the involvement of marginalized communities in the research, policy, and lawmaking process to help ensure that these voices are reflected in the decisions. Although there may not be a perfect solution, policies that reflect the viewpoints of less powerful segments of society will go far in ensuring more fairness and equity. The next article in this series will suggest how the legal system may respond to these concerns.

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<sup>196</sup> *Id.*