

# Editing Embryos: Considering Restrictions on Genetically Engineering Humans

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*In April 2015, scientists used a new genetic engineering tool known as CRISPR to edit the genes of a human embryo for the first time. CRISPR has made gene editing cheaper, more efficient, and more accurate than ever before. These advances in technology indicate that in the near future, technology will enable the genes of embryos to be edited, leading to the birth of the first “genetically modified human.” This Note explores the potential benefits and risks of editing embryos for reproductive purposes, and problematizes the lack of meaningful public regulation or deliberation in the United States on editing embryos. Given this risk of misuse, the United States needs to democratically develop regulations that ensure that the free market is not the only constraint on the practice of genetically modifying embryos.*

*In order to demonstrate these points, this Note evaluates the potential beneficial uses for editing embryos, and weighs those benefits against the potential dangers of editing embryos. In discussing the dangers, it discusses individual health and safety risks, as well as societal risks, including the possibility that embryo editing facilitates a new type of eugenics. After evaluating the promises and perils of edited embryos, it discusses the lack of regulatory oversight of editing embryos in the United States, as compared to other technologically advanced countries. Given the lack of limits on genetically modifying embryos in the United States, and the dangers that editing embryos pose to individuals and society, thoughtful public policy discussion on how to regulate this technology is needed. This Note proposes several recommendations for how the law can help facilitate democratic discussion about whether, or under what circumstances, editing embryos should be permitted. Finally, this Note addresses two arguments that may be raised against regulation, and analyzes why neither of these arguments provide a strong reason to reject regulation.*

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## INTRODUCTION

A scene from the 1997 science fiction film *Gattaca* depicts a married couple's decision to have their second child with the assistance of a clinician, who used the couples' reproductive materials to create four embryos.<sup>1</sup> The clinician edited the genes of each embryo to match the couple's specifications—a boy with hazel eyes, dark hair, and fair skin.<sup>2</sup> The gene editing eradicated any potentially "prejudicial" conditions from the four embryos, such as premature baldness, myopia, alcoholism, propensity for violence, and obesity.<sup>3</sup> Now, the couple has the option to choose which of the four embryos will ultimately become their future child.<sup>4</sup> At one point, the couple questions whether editing the embryo has gone too far, and whether they should leave some of their child's genetic traits to chance.<sup>5</sup> The clinician pushes back against the couple's concerns, telling them, "you want to give your child the best possible start, believe me we have enough imperfection already. Your child doesn't need any additional burdens. Keep in mind this child is still you, simply the best of you. You could conceive naturally a thousand times and never get such a

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1. *GATTACA* (Columbia Pictures 1997).

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

result.”<sup>6</sup> At the time of its release in 1997, *Gattaca* was likely dismissed as the fictional product of imaginative Hollywood minds. However, nearly twenty years later, the process of editing the genes of embryos (hereinafter “editing embryos”) is gradually becoming a reality.

In April 2015, scientists used a new genetic engineering tool known as clustered regularly interspaced short palindromic repeats (“CRISPR”) to edit embryos for the first time.<sup>7</sup> Gene editing using CRISPR involves altering the genetic sequences in an embryo.<sup>8</sup> CRISPR could be used to eliminate genes from embryos that directly correspond to lifelong conditions, such as deafness.<sup>9</sup> CRISPR could also be used to eliminate genes that have a correlation to diseases that arise later in life, such as eliminating the breast cancer susceptibility gene (“BRCA”) mutations associated with breast and ovarian cancer.<sup>10</sup> In order to accomplish gene editing, clinicians need to pursue several initial steps, including: creating embryos using in vitro fertilization (“IVF”), analyzing the genomes of the embryos, and identifying embryos that have the specific monogenetic disorder (known as pre-implantation genetic diagnosis, commonly referred to as “PGD”).<sup>11</sup> Then, a clinician would use CRISPR to correct or eliminate the gene that causes the disorder in the embryo.<sup>12</sup> Finally, the edited embryo would be implanted, and if successful, a pregnancy would ensue.<sup>13</sup>

Any genetic alterations to embryos using CRISPR would also be passed down to future generations.<sup>14</sup> This is because editing embryos involves making changes to germline DNA.<sup>15</sup> Changes to germline DNA are permanent and heritable, meaning that an individual with these changes will pass them down to all of her genetically related children.<sup>16</sup> Thus, by using embryo editing to modify the genes of one’s child, you are also modifying the genes of your grandchildren, great-grandchildren, and so forth. Molecular technology has been used to conduct genetic modifications for decades, facilitating the rise of genetically modified

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6. *Id.*

7. See Puping Liang et al., *CRISPR/Cas9-Mediated Gene Editing in Human Trippronuclear Zygotes*, 6 *PROTEIN & CELL* 363 (2015); see also 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> (last visited Aug. 5, 2016).

8. Cyranoski & Reardon, *supra* note 7.

9. Eric S. Lander, *Brave New Genome*, 373 *NEW ENG. J. MED.* 5, 6 (2015).

10. Zoë Corbyn, *Crispr: Is It a Good Idea to ‘Upgrade’ Our DNA?*, *THE GUARDIAN* (May 10, 2015, 2:30 PM), <https://www.theguardian.com/science/2015/may/10/crispr-genome-editing-dna-upgrade-technology-genetic-disease> (last visited Aug. 5, 2016).

11. Lander, *supra* note 9, at 6.

12. *Id.*

13. *Id.*

14. Cyranoski & Reardon, *supra* note 7.

15. *Id.*

16. *Id.*

organisms (“GMOs”). However, CRISPR makes genetic modifications cheaper, easier, and more accurate than ever before.<sup>17</sup> With this new cheap and easy way to conduct genetic modifications, it is increasingly likely that embryos will one day be edited and used to create genetically modified humans.<sup>18</sup> CRISPR has thus fast-tracked the potential for individuals to exercise a great measure of control over the genetic makeup of their future children.

At this time, editing embryos using CRISPR has only been conducted for research purposes, as opposed to reproductive purposes, meaning that no edited embryos have been used to initiate a pregnancy.<sup>19</sup> Initial experiments using CRISPR to edit embryos demonstrated that such editing is currently neither safe, nor effective for reproductive purposes.<sup>20</sup> Researchers predict, however, that technology like CRISPR will continue to be refined, eventually leading to the ability to successfully edit embryos for reproductive purposes.<sup>21</sup> Just as other types of reproductive technology—such as prenatal screening, in-vitro fertilization, and preimplantation genetic diagnosis—have progressed from research to practice, so too could editing embryos. At some point in the not-too-distant future, technology will enable individuals to genetically modify embryos, implant those modified embryos, and to create the first genetically modified children.<sup>22</sup> By the time science reaches this point, edited embryos could be in high demand.<sup>23</sup>

The potential to use CRISPR to edit embryos and create genetically modified humans has sparked discussions on whether or how this technology should be used.<sup>24</sup> For some, the desire to control our genetic

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17. Heidi Ledford, *CRISPR, the Disruptor*, NATURE NEWS (clarified June 8, 2015), <http://www.nature.com/news/crispr-the-disruptor-1.17673>.

18. *Id.*

19. Cyranoski & Reardon, *supra* note 7.

20. Liang et al., *supra* note 7; Lander, *supra* note 9, at 6.

21. Katrine S. Bosley et al., *CRISPR Germline Engineering—The Community Speaks*, 33 NATURE BIOTECHNOLOGY 478, 478–79 (2015).

22. *Id.*

23. See Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKELEY TECH. L.J. 897, 935 (2007) (citing public opinion polls from 1986 and 1992 that demonstrate that forty to forty-five percent of the American public approved of gene therapy to enhance physical and intellectual traits). Suter also noted that “[a]lthough genetic enhancement ‘may indeed be very far down the road,’ for technological reasons, ‘the potential demand may be so great that private companies may soon begin making a substantial commitment toward enhancement research and development.’” *Id.* at 934 n.195 (citing LORI B. ANDREWS ET AL., *GENETICS: ETHICS, LAW AND POLICY* 439–40 (2d ed. 2006)).

24. Cyranoski & Reardon, *supra* note 7; Nathaniel Comfort, *Can We Cure Genetic Diseases Without Slipping into Eugenics?*, THE NATION (July 16, 2015), <http://www.thenation.com/article/can-we-cure-genetic-diseases-without-slipping-into-eugenics/> (last visited Aug. 5, 2016) (contrasting CRISPR “liberals” and “conservatives”); see Marcy Darnovsky, *The Perils of Human Gene Editing for Reproduction*, WASH. EXAMINER (Mar. 8, 2016, 12:01 AM), <http://www.washingtonexaminer.com/the-perils-of-human-gene-editing-for-reproduction/article/2585173> (last visited Aug. 5, 2016); Bosley et al., *supra* note 21; Erika Check Hayden, *Should You Edit Your Children’s Genes?*, 530 NATURE 402 (2016); Lander, *supra* note 9.

future is a prospect too appealing to resist.<sup>25</sup> But others worry that editing embryos may deepen inequality and create new types of injustices.<sup>26</sup> There have been ongoing debates about the ethical implications and legal rights surrounding genetic reproductive technology like editing embryos.<sup>27</sup> Many who advocate for liberal use of embryo editing focus on the potential to eradicate diseases and improve human health by fixing “imperfections” in human genes.<sup>28</sup> Some have suggested that editing embryos could be used to enhance complex human traits like intelligence.<sup>29</sup> Conversely, on the other side of the debate, individuals have raised concerns about editing embryos.<sup>30</sup> At this time, health and safety risks of this technology preclude it from being used for reproductive purposes.<sup>31</sup> Many concerns about editing embryos, however, focus on broader ethical and societal implications of this technology.<sup>32</sup> Editing embryos could exasperate inequality because only the economically privileged would have the financial means to access procedures for editing embryos.<sup>33</sup> It could also increase discrimination by perpetuating stereotypes about which types of people are more or less desirable.<sup>34</sup> Editing embryos has also been criticized as a new form of eugenics, because this technology

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25. See e.g., John Harris, *Why Human Gene Editing Must Not Be Stopped*, THE GUARDIAN (Dec. 2, 2015, 11:37 AM), <https://www.theguardian.com/science/2015/dec/02/why-human-gene-editing-must-not-be-stopped> (last visited Aug. 5, 2016).

26. See e.g., Darnovsky, *supra* note 24.

27. Legal scholars have considered whether selecting the genes of one's offspring is central to the constitutional right to procreate. See Andrew B. Coan, *Is There a Constitutional Right to Select the Genes of One's Offspring?*, 63 HASTINGS L.J. 233, 240–46 (2011) (analyzing whether it would be desirable for courts to protect the right to select a child's genes); John A. Robertson, *Assisting Reproduction, Choosing Genes, and the Scope of Reproductive Freedom*, 76 GEO. WASH. L. REV. 1490, 1506–11 (2008) (arguing that selecting genes is central to the decision of whether to reproduce); John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 422–23 (1996) [hereinafter Robertson, *Genetic Selection*]. Law Professor Sonia M. Suter has analyzed the ways that genetic reproductive technologies create a “neoeugenics.” Suter, *supra* note 23, at 898–901. Several philosophers and bioethicists argue that creating more perfect humans is a moral imperative once the technology can be effectively applied; see also Julian Savulescu, *In Defence of Procreative Beneficence*, 33 J. MED. ETHICS 284 (2007); NICHOLAS AGAR, LIBERAL EUGENICS: IN DEFENSE OF HUMAN ENHANCEMENT II (2004); Nick Bostrom, *Human Genetic Enhancements: A Transhumanist Perspective*, 37 J. VALUE INQUIRY 493 (2003). Other philosophers focus on the ethical problems raised by choosing the genes of a future child. See e.g. Michael J. Sandel, *The Case Against Perfection: What's Wrong with Designer Children, Bionic Athletes, and Genetic Engineering*, THE ATLANTIC (Apr. 2004), <http://www.theatlantic.com/magazine/archive/2004/04/the-case-against-perfection/302927/> (last visited Aug. 5, 2016).

28. Harris, *supra* note 25; see Cyranoski & Reardon, *supra* note 7.

29. Bostrom, *supra* note 27, at 493; Savulescu, *supra* note 27, at 248–88.

30. See Darnovsky, *supra* note 24; Comfort, *supra* note 24; Sandel, *supra* note 27; Tim Stainton, *Missing the Forest for the Trees? A Disability Rights Take on Genetics*, 13 J. ON DEV. DISABILITIES 89 (2007).

31. Darnovsky, *supra* note 24; Lander, *supra* note 9, at 2–3.

32. Marcy Darnovsky, *Human Gene Editing Is a Social and Political Matter, Not Just a Scientific One*, THE GUARDIAN (Dec. 4, 2015, 8:13 AM), <https://www.theguardian.com/science/2015/dec/04/human-gene-editing-is-a-social-and-political-matter-not-just-a-scientific-one> (last visited Aug. 5, 2016).

33. Comfort, *supra* note 24.

34. Darnovsky, *supra* note 24.

focuses on improving humans by perfecting or bettering human genomes.<sup>35</sup> Those who hope CRISPR will one day be liberally used to improve genes do not see this similarity to eugenics as a problem,<sup>36</sup> but others contend that a eugenic focus on improving human genes stratifies society and moves attention away from social problems.<sup>37</sup>

Given the current safety concerns associated with embryo editing, professional organizations have considered what restrictions should be placed on such editing for research or reproductive purposes.<sup>38</sup> In December 2015, an international summit brought together scholars from scientific academies in the United States, United Kingdom, and China, to discuss human gene editing.<sup>39</sup> As one would suspect, a central issue of the summit was whether there should be limits on embryo editing.<sup>40</sup> The organizers issued a joint statement at the closing of the summit, concluding that, if “human embryos or germline cells undergo gene editing, the modified cells should not be used to establish a pregnancy.”<sup>41</sup> In effect, this statement shut down embryo editing for reproductive purposes for now. However, the group also concluded that, “as scientific knowledge advances and societal views evolve, clinical use of germline editing should be revisited on a regular basis.”<sup>42</sup> The statement thus left open the possibility of initiating a pregnancy using an edited embryo once gene-editing techniques become safer and more effective.<sup>43</sup> As the science behind editing embryos inevitably becomes more precise, it may seem more appealing to researchers and the public.

The statement adopted by the international summit on gene editing also demonstrates one of the only types of current restrictions on such editing in the United States: self imposed regulations by professional organizations. There are currently no laws in the United States that place specific restrictions on editing embryos.<sup>44</sup> In contrast, forty countries have

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35. See Comfort, *supra* note 24; TROY DUSTER, *BACKDOOR TO EUGENICS* (2d ed. 2003); see also Robert Sparrow, *A Not-so-New Eugenics*, 41 HASTINGS CTR. REP. 32, 39–40 (2011) (discussing similarities between old eugenic practices and advocates of a “new eugenics” or “liberal eugenics” through autonomous use genetic technologies to enhance human biology); Tom Koch, *Enhancing Who? Enhancing What? Ethics, Bioethics, and Transhumanism*, 35 J. MED. & PHIL. 685, 685 (2010) (arguing that using genetic selection technology to improve the lives of individuals or society is “a new riff on the old eugenics tune”); Suter, *supra* note 23, at 923 (arguing that contemporary attitudes about reproduction combined with technological developments has moved back toward a new form of eugenics).

36. For example, Nick Agar embraces the concept of “liberal eugenics.” See AGAR, *supra* note 27.

37. Comfort, *supra* note 24.

38. NAT’L ACADS. OF SCIS., ENG’G, MED., ON HUMAN GENE EDITING: INTERNATIONAL SUMMIT STATEMENT (2015); Edward Lanphier et al., *Don’t Edit the Human Germ Line*, 519 NATURE 410, 411 (2015).

39. Darnovsky, *supra* note 32.

40. *Id.*

41. NAT’L ACADS. OF SCIS., ENG’G, MED., *supra* note 38.

42. *Id.*

43. See *id.*

44. See Darnovsky, *supra* note 32.

prohibited the editing of embryos by law.<sup>45</sup> In addition, twenty-one countries have signed a binding Council of Europe treaty which prohibits editing embryos.<sup>46</sup> The United States, however, notably declined the opportunity to sign the Council of Europe treaty.<sup>47</sup> In addition, comparable countries that allowed embryo editing have, unlike the United States, enacted comprehensive regulatory systems governing the permitted uses of this technology. For example, while the United Kingdom does not have any laws outlawing embryo editing, it has an oversight body that specifically regulates the use of genetic reproductive technology.<sup>48</sup> This oversight body is known as the Human Fertilisation and Embryology Authority (“HFEA”).<sup>49</sup> In February 2016, the United Kingdom’s HFEA decided to allow researchers to edit embryos for research purposes.<sup>50</sup> HFEA’s approval of embryo editing in the United Kingdom demonstrates that before long, the researchers in the United States will want to join in on researching the editing of genes of embryos. But unlike the United Kingdom, no federal entity in the United States has the ability to conduct a meaningful analysis of the complex ethical questions and societal consequences involved in editing embryos.

This Note explores the potential benefits and risks of editing embryos for reproductive purposes, and problematizes the lack of meaningful public regulation or deliberation in the United States on such editing. Furthermore, this Note argues that thoughtful public policy discussion on how to regulate this technology is urgently needed. A firm conclusion about whether, or what types of, genetic modification on embryos should be allowed requires a comprehensive evaluation that is too complex to be addressed here. Instead, the purpose of this Note is to show that the risks to individuals and the societal consequences of editing embryos call for democratic deliberation about how to best regulate this technology.

Part I briefly evaluates the potential beneficial uses of editing embryos, and weighs those benefits against the potential dangers. In discussing the dangers, Part I examines individual health and safety risks, as well as societal risks, including the possibility that editing embryos

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45. *Id.*

46. *Id.*; 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, Apr. 4, 1997, 4 E.T.S. No. 164, <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> (last visited Aug. 5, 2016).

47. See Darnovsky, *supra* note 32; Convention for the Protection of Human Rights, *supra* note 46.

48. Human Fertilisation and Embryology Act 2008, c. 22 (U.K.); Human Fertilisation and Embryology Act 1990, c. 37 (U.K.); see ERIK PARENS & LORI P. KNOWLES, REPROGENETICS AND PUBLIC POLICY: REFLECTIONS AND RECOMMENDATIONS, HASTINGS CTR. REP. (SPECIAL SUPP.) S15–S16 (2003).

49. Human Fertilisation and Embryology Act 2008, c. 22.

50. Haroon Siddique, *British Researchers Get Green Light to Genetically Modify Human Embryos*, THE GUARDIAN (Feb. 1, 2016, 8:12 AM), <https://www.theguardian.com/science/2016/feb/01/human-embryo-genetic-modify-regulator-green-light-research> (last visited Aug. 5, 2016).

facilitates a new type of eugenics. After evaluating the promises and perils of edited embryos, Part II discusses the lack of regulatory oversight in the United States, as compared to other technologically advanced countries. Part II then proposes several recommendations on how the law can help facilitate much needed discussion about whether embryo editing should be permitted, and if so, under what precise circumstances it should be permitted. Finally, Part III discusses two arguments against regulating the editing of embryos, and explains why neither argument reasonably justifies the rejection of regulation.

#### I. EVALUATING THE PRACTICE OF GENETICALLY EDITING EMBRYOS

The first step in determining what role the law should play in regulating embryo editing is to evaluate the potential benefits and dangers of this technology. If used properly, editing embryos could potentially alleviate suffering and eradicate diseases. However, if misused, these genetic technologies pose risks to individuals and to society more broadly. This Part explains that the most commonly cited reason to pursue editing embryos is to eradicate diseases from future generations. It also discusses the potential “enhancement” benefits—such as improving human traits like intelligence or life-span beyond normal measures—of editing embryos, which several commentators have proposed may one day be possible. After discussing potential benefits, this Part highlights three potential dangers of editing embryos. First, it will discuss individual health and safety risks. Second, it will discuss risks at the societal level, such as undermining social justice, equality, and inclusivity. It also emphasizes that focusing on genetic improvements to embryos, rather than improvements in social programs, may draw attention away from the social problems that shape health outcomes. Finally, it will analyze how genetic modification of embryos is a type of “backdoor eugenics,”<sup>51</sup> and emphasizes how many ideological assumptions from the American eugenics movement have been rearticulated today in arguments in favor of editing embryos. While this evaluation of benefits and dangers does not aim to be comprehensive, it serves as a demonstration of why deliberation is urgently needed to determine what role of the law in the United States should be with respect to editing embryos.

#### A. POTENTIAL BENEFITS

The most frequent justification given by proponents of embryo editing is that gene editing could reduce the possibility that children will be born with serious genetic diseases.<sup>52</sup> Editing embryos has the potential to allow individuals to avoid passing on serious monogenic diseases, such

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51. See DUSTER, *supra* note 35.

52. Lander, *supra* note 9, at 6.

as Huntington's disease and Tay Sachs disease, which are caused by a single gene.<sup>53</sup> There are roughly 3600 rare monogenic disorders caused by known genes, which could be eliminated from an embryo.<sup>54</sup> Editing embryos would be most beneficial in situations when many or all embryos would be affected by a monogenic disease.<sup>55</sup> This is because those with only a few affected embryos could still use existing reproductive technology to select an unaffected embryo.<sup>56</sup> Individuals with many or all affected embryos, however, would not be able to easily select an unaffected embryo, and thus stand to benefit from being able to edit an affected embryo.<sup>57</sup>

In addition to editing out rare monogenetic disorders, the process above might also be used to edit genes in embryos that correlate to a risk factor for common diseases, such as cancer, diabetes, heart disease, or multiple sclerosis.<sup>58</sup> For example, an embryo might be edited to repair a mutation on the BRCA genes associated with increased risk of breast and ovarian cancer.<sup>59</sup> These changes will be more difficult, however, because the genetic link to an increased risk of a common disease is often polygenetic, meaning that *multiple* genes, rather than a monogenetic link to a single gene, cause the increase in risk.<sup>60</sup> Despite these challenges, some contend that editing embryos provides a uniquely promising way to eradicate and permanently increase resistance to diseases because changes made to one embryo will be passed down to future generations.<sup>61</sup>

In addition to preemptively eliminating or reducing the risk of diseases, some believe that eventually embryo genes could be "enhanced" with other types of desirable genetic features that are currently not present or common in the human population.<sup>62</sup> This so-called "enhancement" use of editing embryos proposes to provide a future child with complex traits, such as athleticism or intelligence.<sup>63</sup> Philosophy professor Nick Bostrom contends that technology like editing embryos should one day be used for "radical extension of human health-span,

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53. *Id.*

54. *Id.*

55. *Id.*

56. *Id.*

57. *Id.*

58. *Id.*

59. Corbyn, *supra* note 10.

60. Lander, *supra* note 9, at 6.

61. Harris, *supra* note 25.

62. See Corbyn, *supra* note 10 (discussing possible enhancement uses of gene editing); Antonio Regalado, *Engineering the Perfect Baby*, MIT TECH. REV. (Mar. 5, 2015), <https://www.technologyreview.com/s/535661/engineering-the-perfect-baby/> (discussing the views of enhancement advocates). See generally Bostrom, *supra* note 27; Savulescu, *supra* note 27; JOHN A. HARRIS, ENHANCING EVOLUTION: THE ETHICAL CASE FOR MAKING BETTER PEOPLE (2010) (for discussions by those advocating for genetic enhancement).

63. David B. Resnik & Daniel B. Vorhaus, Commentary, *Genetic Modification and Genetic Determinism*, PHIL., ETHICS, & HUMAN. IN MED. (June 26, 2006), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1524970/> (last visited Aug. 5, 2016).

eradication of disease, elimination of unnecessary suffering, and augmentation of human intellectual, physical, and emotional capacities.”<sup>64</sup> Bostrom has also described genetic modification as the next step forward in human evolution.<sup>65</sup> Julian Savulescu, also a philosophy professor and proponent of the enhancement of genes, argues that creating the genetically “best children” is morally *required*, an imperative that follows from the principle of beneficence.<sup>66</sup> A group known as the “Genetic Virtue Project” considered whether embryos could be modified to have “virtuous” temperaments, such as a propensity for nonviolence or empathy.<sup>67</sup> All of these discussions demonstrate that some believe that editing embryos could do more than simply improve health, by providing future generations with heightened physical and mental capabilities.

While these visions of enhancement may sound appealing, the link between genes and complex traits like intelligence is largely unknown.<sup>68</sup> Any polygenetic link to complex traits would be difficult to establish.<sup>69</sup> This is because it is difficult to isolate the genetic component of complex traits, such as intelligence, from environmental and other factors, which often have no universal definition. In addition, editing embryos for enhancement purposes rests on a strong presumption of genetic determinism—the presumption that a gene or genes almost always leads to the development of a particular trait.<sup>70</sup> This type of genetic determinism has been criticized as scientifically inaccurate because most genes play only a probabilistic role in determining complex traits, as environment and development play a large role in gene expression.<sup>71</sup> In addition, many complex traits are socially constructed, rather than based in biology, making it difficult to conduct objective studies on how genes relate to these complex traits.<sup>72</sup> While these problems demonstrate that it may not be feasible to edit embryos for enhancement purposes, a large portion of the public may be open to the idea.<sup>73</sup> For many, genetic enhancement may

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64. Bostrom, *supra* note 27, at 493.

65. *See id.* at 495; *see also* Owen D. Jones, *Reproductive Autonomy and Evolutionary Biology: A Regulatory Framework for Trait-Selection Technologies*, 19 AM. J.L. & MED. 187, 187 (1993).

66. *See* Savulescu, *supra* note 27, at 286 (arguing that the principle of beneficence requires individuals using IVF to choose the “best of the available embryos”).

67. Mark Walker, *Enhancing Genetic Virtue: A Project for Twenty-First Century Humanity?*, 28 POL. & LIFE SCIS. 27, 27 (2009). The Genetic Virtue Project is an interdisciplinary project between scientists, philosophers, and doctors to enhance human ethics by finding, and engineering for, genetic correlates to “virtuous” behavior. *See id.* at 27–28.

68. Ulric Neisser et al., *Intelligence: Knowns and Unknowns*, 51 AM. PSYCHOLOGIST 77, 96 (1996).

69. Resnik & Vorhaus, *supra* note 63 at 3–6.

70. *Id.*

71. *Id.*

72. HELEN E. LONGINO, *STUDYING HUMAN BEHAVIOR: HOW SCIENTISTS INVESTIGATE AGGRESSION AND SEXUALITY* 135–36 (2013).

73. *See* Suter, *supra* note 23, at 925 n.157; Rick Weiss, *Cosmetic Gene Therapy's Thorny Traits*, WASH. POST, Oct. 12, 1997, at A1 (“Public opinion polls suggest that the demand for genetic enhancements may be

be the next step in giving children every possible chance at success. Thus, even if strong links between genes and complex traits cannot be established with scientific credibility, edits that involve even a slight or a purported chance of improving certain traits could become popular.<sup>74</sup>

In sum, the strongest argument for editing embryos is that it could eliminate genes linked to diseases from future generations. Eventually, with increased knowledge about the correlations between genetic risk factors and improved accuracy in genetic modification techniques, embryos might be edited to reduce risk of common diseases. Some proponents also contend that technology like embryo editing will ultimately facilitate “enhancement” of embryos, by endowing children with nonmedical advantages, such as heightened intelligence. Scientific evidence linking complex nonmedical traits to genes, however, is lacking. Even discussions about whether the feasible medical applications of editing embryos should be carried out must involve a weighing of the potential benefits against the potential dangers.

## B. POTENTIAL DANGERS

There are at least four compelling reasons to consider regulating embryo editing for reproductive purposes. First, editing embryos poses serious health and safety risks.<sup>75</sup> Second, allowing embryos to be edited involves societal risks, by potentially deepening social and economic inequalities.<sup>76</sup> Forcing on the promises of editing embryos may also lead to undesirable societal consequences by moving attention away from social problems, and framing these problems as individual genetic problems.<sup>77</sup> Finally, editing embryos potentially involves ideals from the American eugenic era by encouraging reproduction of good genes and discouraging reproduction of bad genes.<sup>78</sup> The framework for evaluating whether to allow the editing embryos should focus on these dangers.

### 1. Individual Health & Safety Risks

There are many health and safety risks associated with editing embryos.<sup>79</sup> Some of these risks will be removed through advances in science and technology, but others are inherent problems with embryo

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substantial. Surveys in 1986 and 1992 showed that 40 percent to 45 percent of the American public approved of the concept of using genes to bolster physical and intellectual traits.”).

74. Darnovsky, *supra* note 24 (contending that even if genetically modified children are simply purported to be more intelligent, that the social outcomes could be problematic).

75. Lander, *supra* note 9, at 6; *id.*

76. See Darnovsky, *supra* note 24; Sandel, *supra* note 27, at 57–58; Stainton, *supra* note 30, at 90; Koch, *supra* note 35; Suter, *supra* note 23, at 922–23.

77. See Comfort, *supra* note 24.

78. *Id.*; Koch, *supra* note 35, at 687; Suter, *supra* note 23, at 922–23.

79. See, e.g., Lander, *supra* note 9, at 6.

editing that cannot be obviated.<sup>80</sup> Currently, the genetic editing of embryos for reproductive purposes is a risky form of human experimentation. Technical problems prevent scientists from editing embryos with sufficient accuracy and precision.<sup>81</sup> For example, the first experiment on editing embryos involved problems with incomplete changes to targeted genes, inaccurate modification of genes, and unintentional changes to genes.<sup>82</sup> Each of these problems with making precise and accurate changes to an embryo's genome would lead to devastating effects for a human.<sup>83</sup>

Even once gene editing precision and accuracy improves, there will still be inherent risks in conducting gene editing on embryos. Scientists lack the ability to accurately predict all of the consequences of gene editing because edits to one gene can have unexpected consequences elsewhere in a genome that only become apparent over time.<sup>84</sup> One instance of this arose when researchers conducting experiments on mice modified a gene to protect against cancer, but unexpectedly found that the modification also caused premature aging.<sup>85</sup> It is also well known that genes that decrease the risk for one disease may also increase the risk for another.<sup>86</sup> For example, genetic mutation that protects against HIV also happens to increase the risk for West Nile virus.<sup>87</sup> These long-term health consequences of editing embryos may not be known until years after the edits have been conducted.<sup>88</sup>

Editing embryos will simply never be risk-free. Mistakes are not only unavoidable, but also irreversible, because edited genes cannot be easily removed once present in the human population.<sup>89</sup> While scientist may think they are making improvements in the genome, the improvements may actually create serious problems down the line. Even assuming the process of editing embryos becomes safer and more accurate, these inherent risks demonstrate that policies should be crafted to determine whether and how gene editing should be used on embryos.

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80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.*

84. *Id.*

85. *Id.* at 7 (citing Stuart D. Tyner et al., *P53 Mutant Mice that Display Early Ageing-Associated Phenotypes*, 451 NATURE 45, 45-53 (2002)).

86. *Id.* at 6.

87. *Id.*

88. See Darnovsky, *supra* note 24.

89. *Id.*

## 2. *Societal Consequences*

In addition to individual harms, there may be undesirable social consequences of editing embryos. First, editing embryos might increase intolerance of people with disabilities. Disability rights advocates have argued that reproductive decisions that aim to eliminate people with disabilities have a damaging effect on people currently living with disabilities. Second, editing embryos may perpetuate broader social and economic inequalities. Finally, by focusing too heavily on individual genetic problems, editing embryos may turn attention away from social problems more broadly. Embryo editing involves a powerful mix of technology and science, and the United States should consider whether regulation of such editing could potentially alleviate some of the dangerous societal consequences.

Technologies like editing embryos have been criticized from a disability rights standpoint.<sup>90</sup> Disability rights advocates and scholars have already pointed out how other types of genetic selection technologies, including prenatal screening and PGD, have allowed society to selectively eliminate people with disabilities, such as reducing the number of people born with Down syndrome.<sup>91</sup> Similarly, editing embryos would allow people to eliminate future children with genes linked to disabilities. But unlike prenatal screening and PGD, editing embryos goes a step further by giving parents the power to eliminate disabilities from future generations. Several specific criticisms from disability right advocates, which have been raised about prenatal screening and PGD, also apply in the context of editing embryos.

Focusing on embryo editing as a method for preventing disabilities before they occur may hinder attempts to restructure the world in a way that makes living with disabilities less burdensome.<sup>92</sup> Focusing on embryo editing as a way to eliminate disabilities as a result places a burden on individuals to utilize that technology. Perhaps, instead of focusing on individual responsibility to eliminate disabilities, the focus ought to be on implementing strong public policies to eliminate the disadvantages that people with disabilities may face. In addition, many individuals have

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90. Hayden, *supra* note 24 (discussing the impact of gene editing on communities living with genetic differences); Stainton, *supra* note 30; Eric Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing Reflections and Recommendations*, 29 HASTINGS CTR. REP. (SPECIAL SUPP.) S1, S2 (1999).

91. See Renate Lindeman, *Down Syndrome Screening Isn't About Public Health. It's About Eliminating a Group of People*, WASH. POST (June 16, 2015), <https://www.washingtonpost.com/posteverything/wp/2015/06/16/down-syndrome-screening-isnt-about-public-health-its-about-eliminating-a-group-of-people/> (last visited Aug. 5, 2016).

92. See Tom Shakespeare, *Choices and Rights: Eugenics, Genetics and Disability Equality*, 13 DISABILITY & SOC'Y 665, 669 (1998).

misconceptions about what life is like with a disability, and those misconceptions shape the desire to avoid having a child with a disability.<sup>93</sup> Editing embryos potentially reinforces stereotypes about those disabilities by promoting the message that the presence of a disability necessarily means lower quality of life. Disability rights advocates have pushed back against this presumption, and even argued that some types of disabilities, such as high functioning Autism spectrum disorder, are a form of neurodiversity that society should embrace.<sup>94</sup>

Decreasing the number of individuals living with disabilities also has an impact on the culture of people currently living with such disabilities.<sup>95</sup> If the numbers of people with disabilities decreases, so too will the number of resources dedicated to these groups. Moreover, some parents of people with Down syndrome have described being questioned for their decision to have a child with this trait.<sup>96</sup> This experience demonstrates that, while today society largely treats disability as an immutable trait and product of chance, editing embryos could potentially lead to treating disabilities as the product of individual choice, which can be met with disapproval.<sup>97</sup> Thus, editing embryos may lead to increased intolerance of people with disabilities the future.<sup>98</sup> These concerns demonstrate that decisions about editing embryos are not simply isolated individual decisions. Rather, these decisions will affect many communities, including those with disabilities, if and when editing embryos is used to avoid certain undesirable genes.<sup>99</sup>

In addition to the specific concerns raised by disability rights advocates, editing embryos has the potential to exacerbate already existing broader social and economic inequalities.<sup>100</sup> The costs associated with editing embryos—which is the combined cost of IVF, PGD, and CRISPR—would make it accessible only to those who are already economically advantaged. One round of IVF and PGD alone costs an average of \$13,000–\$16,500, and multiple rounds are often necessary to achieve a successful pregnancy.<sup>101</sup> If the individuals who can afford this technology decide to make use of the opportunity to endow their

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93. Parens & Asch, *supra* note 90, at 111.

94. Pier Jaarsma & Stellan Welin, *Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement*, 20 HEALTH CARE ANALYSIS 20, 22 (2012) (discussing the neurodiversity movement and its claims); see Suter, *supra* note 23, at 955–56.

95. See Suter, *supra* note 23, at 955 (discussing how defining “unfit” in terms of a disability “alone may devalue the lives of those with the trait”).

96. See Rachel Adams, “*Didn’t You Get Tested?*”, SALON (Apr. 28, 2013, 12:00 PM), [http://www.salon.com/2013/04/28/all\\_the\\_ways\\_you\\_judge\\_my\\_son/](http://www.salon.com/2013/04/28/all_the_ways_you_judge_my_son/) (last visited Aug. 5, 2016).

97. See Suter, *supra* note 23, at 955.

98. *Id.*

99. *Id.*

100. *Id.* at 959.

101. *Pre-Implantation Genetic Diagnosis (PGD)*, REPROD. HEALTH TECHS. PROJECT, <http://www.rhnp.org/fertility/pgd/> (last visited Aug. 5, 2016).

children with desirable traits, then undesirable traits may become more frequent among the more socially disadvantaged.<sup>102</sup> Children with genomes edited to include desirable traits would become more frequent among those who already have the greatest advantages in society.

It is also possible that rather than preventing serious genetic diseases, editing embryos will be developed and marketed for common nonmedical needs. While curing devastating, rare genetic diseases is incredibly important work, there is much more economic profit to be made in curing common inconveniences, such as male-pattern baldness or myopia.<sup>103</sup> This focus on commercial uses for genetic technology is evident in a similar field, somatic (that is non-reproductive) gene transfer technology.<sup>104</sup> In that field of research, “the focus of the field has shifted from rare genetic disorders, now viewed as offering limited profits, to more common ailments that promise greater financial gain.”<sup>105</sup> A similar trend has been seen in the field of PGD reproductive technology. PGD began as a service for preventing serious and rare genetic diseases, but today PGD is increasingly being used to select a child’s sex.<sup>106</sup> At least one clinic has openly advertised its desire to soon offer PGD screening for eye and hair color.<sup>107</sup> This trend demonstrates that the original purpose of genetic reproductive technologies—to help individuals have healthy babies—has turned toward appeasing parents’ cosmetic desires. Instead of editing embryos to prevent serious health conditions, this technology could be used for endowing children with desirable cosmetic or nonmedical traits. The potential for embryo editing to be used for profits over health improvements demonstrates that leaving this technology unregulated in the free-market may lead to undesirable consequences from a societal interests perspective.

Additionally, fixating on the potential benefits of embryo editing, especially for enhancement purposes, may put too much emphasis on improving individual biology and distract society from addressing aggregate structural problems. Proponents of embryo editing do not necessarily understand social intervention and genetic intervention to be mutually exclusive, but proponents often mistakenly treat genetic

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102. See Comfort, *supra* note 24; Suter, *supra* note 23, at 959.

103. Mark S. Frankel, *Inheritable Genetic Modification and a Brave New World: Did Huxley Have It Wrong?*, 33 HASTINGS CTR. REP. 31, 34 (2003).

104. *Id.*

105. *Id.*

106. See 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*, 96 FERTILITY AND STERILITY 865, 868 (2011).

107. Gina Salamone, *Custom-Made Babies Delivered: Fertility Clinic Doctor’s Design-a-Kid Offer Creates Uproar*, DAILY NEWS (N.Y.) (Mar. 4, 2009, 1:58 PM), <http://www.nydailynews.com/news/custom-made-babies-delivered-fertility-clinic-doctor-design-a-kid-offer-creates-uproar-article-1.365959> (last visited Aug. 5, 2016); Gautam Naik, *A Baby, Please. Blond, Freckles -- Hold the Colic*, WALL ST. J. (Feb. 12, 2009), <http://www.wsj.com/articles/SB123439771603075099> (last visited Aug. 5, 2016).

solutions as more universally promising than social solutions. Science is on a trajectory which overemphasizes behavioral studies at the individual level, rather than focusing also on the broader levels of groups or populations.<sup>108</sup> For example, behavioral studies of aggression and sexuality mostly look at variation in distribution of individual differences.<sup>109</sup> This approach misses the chance to understand variations in distribution “as effects of causal factors, such as physical environment or social structure, operating at the level of populations.”<sup>110</sup> Similarly, scientists have tended to overemphasize the promise of what genetic research can explain or change about human behaviors, and because of this overemphasis, the public treats genetic research as more promising than social-environmental approaches in terms of their ability to improve human life.<sup>111</sup> The public may certainly be fascinated with the potential to improve human genetics by editing embryos, but this fascination potentially overshadows important conversations about how to best improve society.

Genes certainly play an instrumental role in *biological* health outcomes, but more frequently, public discussions focus on the potential for genetic technology to cure complex *social* problems. For example, social factors like access to education or exposure to violence are key determinates of health, but no amount of genetic engineering can influence those social factors.<sup>112</sup> Overemphasizing genetic change also overemphasizes individual problems, and creating a better society becomes an issue of addressing *individual* traits.<sup>113</sup> The *social* conditions in which people live, which deeply affect individual choices and dispositions, become deemphasized.<sup>114</sup>

Humans and societies are certainly capable of manipulation, but social programs like education, rather than improvements of genes, are critical to improving lives. This calls for developing effective institutions like education, health care, public safety, and other types of public services.<sup>115</sup> Achieving social justice requires advocates to focus not only on individuals exhibiting certain traits, but also on developing institutions that can help lead people toward a fulfilling life and positive contribution to the community. Biotechnology can improve quality of life for some people, but genetic solutions are not the simple fix to complex social

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108. LONGINO, *supra* note 72, at 135–36.

109. *Id.*

110. *Id.* at 136.

111. *Id.* at 135–36.

112. Comfort, *supra* note 24.

113. *Id.*

114. *Id.*; Frankel, *supra* note 103, at 33 (pointing out that trait selection might lead to “less appreciation for productive social interaction in a classroom, for example, or for the hard work traditionally required to become a successful professional. These conventional methods of enhancement may have some intrinsic value that could never be duplicated by a genetic intervention.”).

115. *See id.*

problems. We cannot, as advocates of the liberal use of edited embryos suggest, pull levers to implement change for other people or societies; beliefs and social structures must also change. By perpetuating the belief that perfecting the human genome will cure many ailments of society, discussions of editing embryos also begin to sound remarkably similar to discussions raised in the eugenics movement.

### 3. *Relation to Eugenics*

One important critique of editing embryos involves how this technology relates to eugenics. Eugenics can be understood as both a historical social movement of practices, and a set of beliefs. The historical social movement of eugenics, which reached its peak in the United States in the early twentieth century, is most notoriously associated with forced sterilization policies.<sup>116</sup> Eugenic beliefs aim at improving the genetic quality of the human population by encouraging reproduction of desirable genes or traits and impeding reproduction of undesirable ones.<sup>117</sup>

Commentators have routinely discussed whether gene editing facilitates a new type of eugenics.<sup>118</sup> Like eugenic beliefs, editing embryos rests on the presumption that some genes are more desirable to reproduce than others. In addition, editing embryos may also fulfill the goal of the eugenics movement by providing a high-tech method for “improving” human genetics. This shared presumption has led editing embryos to be described as “neoeugenics,”<sup>119</sup> “backdoor eugenics,”<sup>120</sup> and “liberal eugenics.”<sup>121</sup> According to some, the similarities between eugenic beliefs and editing embryos demonstrates the dangerous societal consequences of engaging in this practice: bringing back eugenics.<sup>122</sup> But others contend that these similarities do not pose a problem because, unlike eugenic practices, editing embryos does not involve state control over reproduction.<sup>123</sup> To explain what is at stake in the debates about whether embryo editing is a form of eugenics, it is important to first place this debate in its broader historical setting, which will be done in the following Subpart.

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116. Daniel J. Kevles, *From Eugenics to Patents: Genetics, Law, and Human Rights*, 75 ANNALS OF HUM. GENETICS 326, 327–28 (2011).

117. *Id.* at 327.

118. *See, e.g.*, Comfort, *supra* note 24.

119. Suter, *supra* note 23, at 923.

120. DUSTER, *supra* note 35, at 129.

121. *See generally* AGAR, *supra* note 27 (discussing the modification of embryos and comparing it to “neoeugenics” and “liberal eugenics”).

122. *See* Comfort, *supra* note 24.

123. AGAR, *supra* note 27, at 5–6.

a. History of Eugenics

Sir Francis Galton coined the term “eugenics” in 1883 to denote his theory of improving humans by giving “the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable.”<sup>124</sup> Galton studied whether selective breeding used in animals could be applied to improve humans by reproducing desirable traits and prohibiting reproduction of undesirable traits.<sup>125</sup> In the early twentieth century, two concurrent intellectual developments helped propel the theory of eugenics into mainstream society: the rediscovery of Mendel’s theory of inheritance and the growing acceptance of Darwin’s theory of evolution.<sup>126</sup> Flowing from the idea of natural selection, eugenic theory proposed that individuals or populations could be improved through intentional reproductive choices, by encouraging reproduction of desirable traits (“positive eugenics”), and inhibiting reproduction of undesirable traits (“negative eugenics”).<sup>127</sup> Eugenacists used genetic and evolutionary theory to give scientific authority to deeply ingrained beliefs about natural rankings of humans held by those in power in order to rationalize maintaining the status-quo social order.<sup>128</sup>

The transition from eugenics as a scientific theory, to eugenic public policy was a response to broader anxieties about how increased immigration would change the ethnic makeup of the American population.<sup>129</sup> In 1905, President Theodore Roosevelt declared that, “race purity must be maintained” through promoting “more native white births.”<sup>130</sup> President Roosevelt’s call to “improve” the genetic quality of the American population aligned with Anglo-Saxon America’s concern about immigration.<sup>131</sup> Legislators used eugenics research on the “contamination of Anglo-Saxon genetic purity” to support the passing of the Immigration Act of 1924.<sup>132</sup> This Act banned the immigration of Arabs and Asians, and severely restricted immigration of Southern Europeans, Eastern Europeans, and Africans.<sup>133</sup> Eugenacists such as Harry Hamilton Laughlin also popularized eugenic policy by linking eugenics with economics and social

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124. DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 4 (1985) (quoting FRANCIS GALTON, *HEREDITARY GENIUS: AN INQUIRY INTO ITS LAWS AND CONSEQUENCES* 37–38 (MacMillan & Co. 1869)). As one might suspect from this quote, Galton’s theory of eugenics was also tied to his beliefs about racial, ethnic, and social hierarchies. *Id.* at 3. For example, he wrote about the heritable “intellectual inferiority” and “impulsive passions” of blacks. *Id.*

125. AGAR, *supra* note 27, at 3.

126. *Id.*

127. See Suter, *supra* note 23, at 903.

128. KEVLES, *supra* note 124, at 3–4.

129. *Id.* at 26.

130. *Id.* at 26 (citing Theodore Roosevelt, Address at the Lincoln Dinner (Feb. 13, 1905)).

131. *Id.*

132. *Id.*

133. Immigration Act of May 26, 1924, Pub. L. No. 68-139, <http://www.legisworks.org/congress/68/publaw-139.pdf>.

inequality.<sup>134</sup> Laughlin told audiences that the so-called “inferior 10 percent” were “an economic burden on the 90 percent and a constant source of danger to the national and racial life.”<sup>135</sup> Eugenic beliefs about natural inferiority of certain populations aligned with the political drive to enact immigration restrictions. Both eugenics and immigration restrictions served as a response to anxieties about the increasing number of people of color in the United States.<sup>136</sup>

The early twentieth century also ushered in the dark turn toward eugenics’ most notorious policy: forced sterilization.<sup>137</sup> Between 1907 and 1963, state governments forcibly sterilized over 60,000 people under eugenics laws.<sup>138</sup> In 1927, the Supreme Court upheld the practice of forced sterilization in *Buck v. Bell*, affirming Virginia’s compulsory sterilization policy that had led doctors to forcibly sterilize a seventeen year-old girl who was allegedly “feebleminded.”<sup>139</sup> In the decision, Justice Holmes famously declared that “[t]hree generations of imbeciles are enough.”<sup>140</sup> With that line, the belief that biology was at the root of America’s social problems—a view that had been decorated with all the trappings of scientific authority for a century—became a sound justification for violating the bodily autonomy and reproductive rights of tens of thousands of Americans.

After World War II, the popularity of eugenic theory and policy faded as Americans became aware of its link to Nazi race science and genocide.<sup>141</sup> While most American eugenic practices discontinued, the reality of sterilization persisted. The Eugenics Board of North Carolina continued involuntary sterilizations until 1974.<sup>142</sup> Doctors in North Carolina sterilized an estimated 8000 people under its eugenics program, primarily targeting young women of color.<sup>143</sup> Even as recently as 2010, doctors in California sterilized at least 148 female prison inmates,

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134. KEVLES, *supra* note 124, at 102–03.

135. *Id.* at 103.

136. *Id.*

137. *Id.*

138. *Id.*

139. *Buck v. Bell*, 274 U.S. 200, 205 (1927). While the Court accepted Virginia’s description of Carrie Buck as a “feeble-minded” woman, researchers who followed up on Ms. Buck years after the case discovered that she was in fact a woman of normal intelligence. See Stephen Jay Gould, *Carrie Buck’s Daughter*, 2 CONST. COMMENT. 331, 336 (1985). For a detailed history on this case, see PAUL A. LOMBARDO, *THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK V. BELL* (2008).

139. *Buck*, 274 U.S. at 207.

140. *Id.*

141. Suter, *supra* note 23, at 915; see *Skinner v. Oklahoma*, 316 U.S. 535, 543 (1942) (holding that a statute sterilizing habitual criminals violated the Fourteenth Amendment); Kevles, *supra* note 116, at 329 (discussing growing opposition to eugenics in the United States).

142. Philip R. Reilly, *Eugenics, Ethics, Sterilization Laws*, in 1 ENCYCLOPEDIA OF ETHICAL, LEGAL & POL’Y ISSUES IN BIOTECHNOLOGY 205, 211 (2000).

143. *Id.*

primarily women of color, without obtaining proper consent.<sup>144</sup> Thus, while states retracted eugenics policies, and public opposition to forced sterilization rose, eugenics never truly disappeared from the United States.

This background helps clarify how editing embryos can be distinguished from past eugenic policy. Forced sterilization practices epitomized eugenic social policy during the early and mid-twentieth century. The eugenic ideology supporting this policy focused on defining traits as desirable and undesirable, and then weeding the bad traits out of society through forced sterilizations. While editing embryos does not involve state control over reproduction, it can be compared to eugenic ideology for facilitating reproduction of desirable traits and discouraging reproduction of undesirable traits.

#### b. Overlap Between Gene Editing & Eugenics

Tackling the question of whether editing embryos is a form of eugenics requires analyzing the similarities and differences between embryo editing and eugenics. The goal of editing embryos relates to eugenics because this technology involves improving individuals through voluntary reproductive choices. Editing embryos is, however, distinct from eugenics because individuals would be free to decide whether or not to use this technology, whereas a hallmark of eugenics was state coercion in reproductive autonomy. Those who advocate for liberal uses of embryo editing believe that the horrors of past state-imposed eugenics should not dissuade the public from embracing genetic modification because such modification would only result from autonomous choices.<sup>145</sup> Critics of editing embryos have pointed out that even if applied through autonomous choices, technology that facilitates eugenics can lead to serious societal consequences.<sup>146</sup> In order to demonstrate these points

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144. In 2013, a report revealed that forced sterilizations had taken place in California state prisons. 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> (last visited Aug. 5, 2016) (reporting that “[d]octors under contract with the California Department of Corrections and Rehabilitation sterilized nearly 150 female inmates from 2006 to 2010 without required state approvals”). Following this report, a California bill was passed into law that banned prisons from performing sterilization procedures on inmates without their consent. See S.B. 1135, 2015–2016 Leg., Reg. Sess. (Cal. 2016) (amending the California penal code to prohibit sterilization of California inmates without first obtaining informed consent).

145. See Arthur L. Caplan, Editorial, *Misusing the Nazi Analogy*, 309 SCI. 535, 535 (2005) (arguing that eugenic principles of the past “have little to do with contemporary ethical debates about science, medicine, or technology”); see also Bostrom, *supra* note 27, at 499 (suggesting “[i]f parents had been left to make the choices for themselves, the worst transgressions of the eugenics movement would not have occurred.”). See generally AGAR, *supra* note 27, at 5 (defending non-therapeutic uses of trait selection and calling human enhancement using reproductive technology “liberal eugenics”).

146. See Comfort, *supra* note 24.

further, the discussion below highlights the primary differences and similarities between eugenics and editing embryos.

Embryo editing differs from eugenics in several key aspects. Perhaps most important, editing embryos is a distinct *practice* of improving humans through intentional reproductive choices, which does not involve state coercion or control. In the eugenics movement, states attempted to improve genetics through policies controlling over-reproduction, including forced sterilization. Conversely, individual reproductive autonomy is central to the editing of embryos, because private individuals will decide whether to edit. This distinction between the practices is critical because forced sterilization practices involved violations of basic bodily and reproductive rights. In that regard, the practice of editing embryos is nothing like past eugenic practices. Editing embryos does not infringe on basic bodily integrity or reproductive autonomy in the same way that sterilizing an individual without her consent does.

Along those same lines, eugenics can be distinguished because eugenics focused on implementing policies at the *state* level, whereas embryo editing focuses on the actions of *private* individuals and industries. Eugenic policy facilitated eugenic beliefs through state laws preventing “undesirable” individuals from reproducing. In contrast, editing embryos for reproductive purposes would only take place through *private* actions or encouragement, not state policy. Private businesses would offer embryo editing services in the free market. Individuals would be free to choose whether to purchase this reproductive service. Further, rather than states mandating what traits are “desirable” or “undesirable,” individuals would make these decisions for themselves.

Embryo editing also diverges from eugenic policies because this technology focuses more on improving individuals than on improving nations or society more broadly. The eugenics movement focused on improving genes in order to fulfill a greater goal of improving a country or humanity as a whole. Today, the development of embryo editing has focused on this technology’s potential to alleviate suffering for *individuals* in future generations.<sup>147</sup> While one might point out that the arguments made by “enhancement” advocates do seem to extend to a greater goal of improving humanity, this argument has not been a central focus for those developing gene editing tools.<sup>148</sup> Instead, embryo editing focused on improvements at the individual level. These distinctions could mean that editing embryos is not meaningfully similar to eugenics. But

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147. See Frankel, *supra* note 103, at 31–32 (listing the most commonly screened for traits).

148. See Bostrom, *supra* note 27, at 502 (arguing that “an enhancement that has both significant intrinsic benefits for an enhanced individual and net positive externalities for the rest of society should be encouraged”); Sparrow, *supra* note 35, at 35 (noting that using trait selection on a widespread scale is still “contingent on the science advancing in certain ways”).

even those who advocate for liberal uses of gene editing have embraced the “eugenic” label, arguing that eugenic goals are only permissible if carried out through autonomous reproductive choices rather than state-imposed coercion.<sup>149</sup> This is because the desire to edit embryos undeniably reflects a type of eugenic belief in improving humans by improving genes.

Although embryo editing differs from eugenics for the reasons discussed above, it still potentially facilitates eugenic beliefs. Embryo editing involves making intentional reproductive choices in order to improve humans by weeding out undesirable genes and reproducing desirable genes.<sup>150</sup> This technology could potentially facilitate both positive and negative eugenics by enabling individuals to edit genes into, and out of, embryos.<sup>151</sup> And by facilitating positive and negative eugenics, even if done through autonomous individual choice rather than state mandate, this technology hardens the lines between traits that are “desirable” and “undesirable.”

The practices of embryo editing and eugenics share several assumptions related to defining “desirable” and “undesirable” traits. Like eugenics, embryo editing has been hailed as a way to alleviate social problems.<sup>152</sup> This view shares with eugenics the assumption that social problems are caused primarily by individuals with bad traits, rather than by the structure of society. It further assumes that genes determine health and behavior, neglecting to recognize the role of social and environmental factors.<sup>153</sup> In addition, like eugenics, embryo editing is premised on the assumption that desirable and undesirable genes can be identified. When individuals advocate for liberal use of embryo editing to improve humans, they assume that we can objectively know which human traits are desirable and would improve life, and which would reduce quality of life. Thus, embryo editing involves the same problematic assumptions as eugenics, by focusing too much on genetic determinism, and by perpetuating the belief that all traits are objectively desirable or undesirable.

In essence, by focusing on “desirable” and “undesirable” traits, editing embryos involves making decisions about which traits make a

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149. See AGAR, *supra* note 27, at 3–16; see also Robertson, *Genetic Selection*, *supra* note 27, at 468 (calling prebirth selection “a form of private eugenics” and arguing that trait selection should be protected as a form of procreative liberty).

150. DUSTER, *supra* note 35; see Koch, *supra* note 35, at 685 (arguing that using genetic selection technology to improve the lives of individuals or society is “a new riff on the old eugenics tune”); Suter, *supra* note 23, at 923.

151. For example, as discussed in more detail *infra* at Part I, genetic modification could prevent a child from being born with Down syndrome, or it could create a child endowed with resistance to common diseases like cancer.

152. See Koch, *supra* note 35.

153. See Comfort, *supra* note 24.

human worthy of value.<sup>154</sup> This technology, like eugenics, potentially perpetuates the belief that a person's genes determine her value in society. Modifying an embryo to make sure that a child will be born with certain traits affirms the belief that people with those traits are the most desirable individuals to reproduce. Decisions about what types of people should be born involve many *subjective* beliefs about what makes a person "better" or "desirable." However, practices like editing embryos have the potential to reify those subjective judgments, and make people believe that certain traits or types of people are universally, *objectively* undesirable or worse-off. The belief that people with certain traits are objectively worse-off is not only inaccurate, but is also problematic because it can lead to stereotypes and prejudices.

Editing embryos could involve weeding out the same types of people targeted by eugenics. For example, eugenics targeted people with disabilities, and editing embryos would also likely be used to eliminate genes linked to disabilities. An argument raised by enhancement advocate Julian Savlescu also helps demonstrate how historically disadvantaged groups could be targeted by editing embryos. Savlescu argues that individuals are morally *obligated* to use technology like editing embryos to select the "best possible" children, which he defines as the children most likely to experience the least amount of suffering.<sup>155</sup> Historian Nathaniel Comfort has pointed out that if Savlescu's argument is followed to its logical conclusion, it calls for creating the same types of people the eugenics movement sought to create. Those with the most chance of success also fall into groups that society privileges. Society currently gives the most opportunities to white, straight, men.<sup>156</sup> Thus, if the goal is to create children that have the best chance of success, this seems to call for eliminating groups like people with disabilities, sexual minorities, and racial minorities.

As this demonstrates, some of our assumptions about what is "desirable" historically, and still today, are grounded in discriminatory attitudes. In particular, people with disabilities, racial minorities, LGBTQ individuals, and women are most vulnerable to these assumptions. The traits, and consequently the type of people Savulescu argues should be edited out of the human genome, end up looking remarkably similar to the types of people that the eugenics movement sought to remove. Thus, if left unregulated, individuals may aim to give their children similar privileged status by editing embryos to fit into the categories of people that get the most opportunities in our society. The ability for editing embryos to provide a new, more efficient method of

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154. See *supra* text accompanying note 151.

155. Savulescu, *supra* note 27, at 284.

156. Comfort, *supra* note 24.

putting eugenic ideology into practice demonstrates that the public needs to establish whether and how this technology can be responsibly used.<sup>157</sup>

Thus, while the individualistic approach that enhancement advocates take is distinct from the eugenics movement, the assumptions underlying their beliefs are far from new. Although proponents are correct to point out how this technology is distinct from eugenics, the differences do not remove the shared ideological assumptions. The ethical concerns raised by these assumptions must be discussed in order to properly determine whether the potential benefits of this technology outweigh the potential harms. The history of the eugenics movement in the United States illustrates how encouraging “desirable” people to reproduce and eliminating the reproduction of “undesirable” people can become a dehumanizing practice. Thoughtful deliberation about how to manage embryo editing, including the possibility of regulation, can help clarify these and other serious concerns raised by this new uncharted technology.

## II. ENVISIONING OVERSIGHT

This Part first discusses how the United States lacks meaningful regulation of embryo editing. It describes the few limits placed on gene editing, including self-imposed regulations by professional organizations, state law, and federal oversight. To demonstrate the absence of regulation in the United States, this Part also outlines the regulatory oversight of research and clinical uses of embryos in the United Kingdom, and discusses the laws outlawing embryo editing in other countries. Finally, this Part draws attention to policies that ought to be considered, and highlights how these policies promote democratic deliberation on how to responsibly use the practice of editing embryos while not overburdening scientific progress.

### A. CURRENT REGULATION IN THE UNITED STATES

Reproductive technology has been described as the “wild west” of American medicine because of the absence of meaningful limits on the uses of these technologies.<sup>158</sup> One reason for the lack of strong regulation is the Dickey-Wicker Amendment, a Congressional bill passed in 1995, which banned all federal funding for embryonic research.<sup>159</sup> As a result, all embryonic research is privately funded.<sup>160</sup> This is problematic because

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157. See generally Comfort, *supra* note 24; Koch, *supra* note 35; DUSTER, *supra* note 35; Sparrow, *supra* note 35 (discussing the dangers of eugenic ideology slipping into the practice of editing embryos and society’s need to establish guidelines for responsible use of the technology).

158. See Marsha Garrison, *Regulating Reproduction*, 76 GEO. WASH. L. REV. 1623, 1623 (2008).

159. Parens & Knowles, *supra* note 48, at S11.

160. *Id.*

research conducted in the private sector is subject to less stringent regulations than publically funded research.

The limited regulations covering genetic reproductive technology in the United States fall within three main categories. First, some professional organizations that research and develop clinical applications of genetic reproductive technology are self-regulated. For example, the American Society for Reproductive Medicine (“ASRM”) sets standards of practice and ethical guidelines for IVF and related procedures that all members must follow.<sup>161</sup> Around ninety percent of providers of reproductive services are members of the ASRM.<sup>162</sup> Second, at the state level, some legislation has been passed to regulate assisted reproduction or aspects of embryo research.<sup>163</sup> For example, New Hampshire and Virginia passed legislation regulating aspects of assisted reproduction.<sup>164</sup> Third, at the federal level, the Food and Drug Administration (“FDA”) has jurisdiction over genetic experiments on embryos because these techniques constitute “products” analogous to other biotechnology products already within the FDA’s mandate.<sup>165</sup> FDA oversight is limited, however, to issues regarding safety and efficacy.<sup>166</sup> Thus, the FDA does not take into account the risk of social harms or threats to individuals that fall outside the scope of *physical* safety.<sup>167</sup> In addition, the FDA does not limit off-label uses of drugs or technologies.<sup>168</sup> If the FDA approves editing embryos for one purpose, it would not be able to prevent editing embryos for other purposes, because these uses would constitute “off-label” use of embryo editing.<sup>169</sup> In sum, none of the standing regulations can promote public conversation about the individual and societal issues that arise in the context of embryo editing.

In comparison, the United Kingdom has taken a much more active regulatory role toward reproductive technology. In the United Kingdom, a previously mentioned federal organization, the Human Fertilisation and Embryology Authority (“HFEA”), regulates genetic reproductive technology. HFEA oversees all research and clinical use of embryos, including genetic modification.<sup>170</sup> The organization grew out of a 1984 federal committee report on assisted reproductive technology and embryonic research, sanctioned in response to the emergence of new

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161. See AM. SOC’Y FOR REPROD. MED., *Revised Minimum Standards for In Vitro Fertilization, Gamete Intrafallopian Transfer, and Related Procedures*, 70 FERTILITY & STERILITY 15 (1998).

162. Parens & Knowles, *supra* note 48, at S12.

163. *See id.*

164. *Id.*

165. *Id.*

166. *Id.*

167. *Id.* In addition, the Fertility Clinic Success Rate and Certification Act requires fertility clinics to report information like success rates to the Centers for Disease Control. *Id.*

168. Darnovsky, *supra* note 24.

169. *Id.*

170. Parens & Knowles, *supra* note 48, at S15.

reproductive technologies at the time, including IVF, cloning, and egg donation.<sup>171</sup> The committee report analyzed ethical issues involved in emerging genetic reproductive technologies, and then recommended adopting a federal system of regulation in the United Kingdom.<sup>172</sup>

In 1990, the government adopted the regulations suggested by the committee report through the Human Fertilisation and Embryology Act, and HFEA was created.<sup>173</sup> Most members of HFEA have scientific expertise, but the regulation system also requires interdisciplinary membership and the input of interest groups.<sup>174</sup> In addition to requiring diverse membership, HFEA also encourages democratic deliberation on reproductive technology policy by serving as a public information resource for patients and practitioners.<sup>175</sup> Parliament updated the Act in 2008, adding new rights and restrictions on genetic reproductive technology, and broadened HFEA's regulatory power.<sup>176</sup> The responsibilities of the organization include the licensing and monitoring of labs and clinics that use IVF, engage in embryo research, or store reproductive materials.<sup>177</sup> HFEA's licensing power is one of its most important regulatory functions.<sup>178</sup> The organization has the power to determine which purposes the research and clinical applications of genetic reproductive technology may be used for. HFEA licensing focuses primarily on licensing for the *purpose* of research and practices, rather than licensing specific *techniques*. This distinction between purposes and techniques prevents regulation from being overly burdensome on scientific and technological development.<sup>179</sup>

Indeed, while the United Kingdom has this comprehensive regulatory framework, the government remains committed to scientific freedom and has "one of the most liberal embryo research policies in the world."<sup>180</sup> For example, in 2015, HFEA allowed researchers in the country to use so-called "three parent IVF," a type of germline genetic modification, to treat infertility and genetic diseases for the first time.<sup>181</sup> And, in February 2016, HFEA permitted a group of scientists to conduct

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171. *Id.*

172. *Id.*

173. *Id.*

174. *Id.* at S16.

175. *Id.* at S15.

176. Some of the primary new elements of the Act included: (1) regulating the creation and use of all human embryos, regardless of how the embryos are created; and (2) banning sex-selection for nonmedical purposes. *Id.*

177. Parens & Knowles, *supra* note 48, at S15.

178. *Id.*

179. *Id.* at S15–S16.

180. *Id.* at S16.

181. James Gallagher, *UK Approves Three-Person Babies*, BBC NEWS (Feb. 24, 2015), <http://www.bbc.com/news/health-31594856> (last visited Aug. 5, 2016); see Darnovsky *supra* note 24, at 127 (explaining how "three parent IVF" is a form of germline modification).

embryo editing for research purposes.<sup>182</sup> These decisions to allow monitored cutting-edge research and clinical use of genetic reproductive technology demonstrate that public regulatory oversight of embryo editing does not necessarily impede development of this technology.<sup>183</sup> Instead, public regulation facilitates democratic deliberation about how this technology should, and should not, be used.

#### B. ADDITIONAL REGULATORY OPTIONS

The United States needs to find better ways to facilitate transparent discussions to evaluate whether, or how, editing embryos should be permitted. Given the risks to both individuals and society outlined above in Part II, three steps should be taken to promote public deliberation over the future research and clinical uses of editing embryo editing.

First, Congress should consider revoking the federal ban on funding for embryonic research. Lifting the ban would allow Congress to invest in the necessary steps toward creating oversight of genetic modification practices. In addition, this move would acknowledge that the United States has already implicitly decided to support embryonic research by allowing the private sector to engage in this research without any restrictions. Responsible oversight begins with the acknowledgement that the United States is already deeply involved in researching potential uses for genetically modified embryos. Opening public funds would allow more regulatory oversight by entities already regulating government funded research.

Second, Congress should create a committee to report legislative recommendations regarding possible formation of a statutorily created body, which would regulate research and clinical uses of genetic reproductive technologies, including the editing of embryos.<sup>184</sup> This commission could consolidate relevant research and writing on the ethical considerations of engaging in research and uses of editing embryos. It should also solicit public opinions and input from stakeholders and expert constituencies that are impacted by this technology. The committee might consider framing recommendations in terms of permissible and impermissible *purposes* for editing embryos, rather than focusing on which *techniques* may be used for modifying embryos.<sup>185</sup> By evaluating the purposes of editing embryos rather than the techniques, the regulations would be less burdensome on scientific progress. The public has an interest in encouraging public and private

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<sup>182</sup> Ewen Callaway, *UK Scientists Gain Licence to Edit Genes in Human Embryos*, NATURE (Feb. 1, 2016), <http://www.nature.com/news/uk-scientists-gain-licence-to-edit-genes-in-human-embryos-1.19270> (last visited Aug. 5, 2016).

<sup>183</sup> Parens & Knowles, *supra* note 48, at S16.

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

<sup>185</sup> *Id.*

developers to invest in research that has promising potential for alleviating serious health problems. If research on promising treatments requires jumping through too many bureaucratic hoops, then researchers may focus their resources elsewhere. The recommendations can outline which purposes of editing embryos are impermissible, which would be allowed with increased regulatory oversight, and which require no oversight beyond the FDA. Furthermore, the commission should consider how to frame legislation such that it would not be too sweeping or reactive. Reproductive technology involves many important nuanced distinctions. Flexible regulation that is capable of adapting to changes in science and society will best fit the needs of these complex issues.

Third, the commission should carefully consider the creation of a standing federal entity that would have authority over both the public and private sectors. The purpose of this entity would be to facilitate public and policy deliberation about research and clinical uses of embryo editing, including the social impacts and the risks to individual well-being. This entity could resemble the United Kingdom's HFEA, with the power to require and grant licenses, monitor facilities, set policy and quality standards, and engage in public consultation. Further, a primary purpose of this entity would be to encourage public conversations about editing embryos. In executing these functions, the agency should consult with all relevant public perspectives, not just the most powerful interest groups. To facilitate this, like the HFEA, a large portion of the members of the U.S. agency should work in industries other than medicine or science in order to prevent industry capture. Congress should consider hiring members that are women, people with disabilities, and people of color, as these groups have special concerns regarding genetic modification, but their voices are largely absent in the private development and use of this biotechnology.<sup>186</sup> In addition, in order to guide the trajectory of the agency, Congress should frame the ethical principles it considers essential to inform the operation of the newly established regulatory agency. Such things could include protecting the well-being and health of children and families, promoting access to IVF for infertile couples, favoring embryo editing for medical purposes over enhancement, and promoting public access to information about embryo editing. The individual, societal, and eugenic consequences of editing embryos demonstrate that public policy discussion on how to regulate this technology is imperative. Deliberations will undoubtedly include many objections to regulation of embryo editing, many of which would focus on broader problems of regulating reproduction. Two of the recognized objections to regulation can be challenged by envisioning alternative frameworks for evaluating regulation of reproductive technology.

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186. Suter, *supra* note 23, at 945.

### III. OBJECTIONS TO REGULATION?

Critics and proponents alike recognize the profound social implications that editing embryos raises, yet many still reject any form of oversight or regulation. Arguments raised against regulation usually reflect two interrelated concerns: (1) weakening reproductive rights and the ability to exercise procreative autonomy; and (2) politicizing science.

#### A. REPRODUCTIVE RIGHTS & PROCREATIVE AUTONOMY

Would increased regulation of editing embryos be a defeat for reproductive rights? Some of the political division that has hampered public action on embryo editing has been blamed on the debate surrounding abortion and other reproductive rights.<sup>187</sup> Some reproductive rights advocates might worry that regulation of embryo editing, which restricts an aspect of reproduction, provides an opening for legal regulations of other aspects of reproduction, such as IVF, contraception, and abortion. Regulation of editing embryos raises alarms in the reproductive rights context because it threatens to chip away at female autonomy by taking choices out of the hands of women and families, and putting those choices into the hands of the government. Many in the pro-choice movement are understandably resistant to policies that conflict with the choice and privacy framework of reproductive rights. The fight for bodily autonomy and the right to decide whether to have children has been hard fought. Regulations on editing embryos thus have enormous practical and symbolic significance, as any regulation on reproductive decisionmaking may be seen as a defeat for other reproductive rights.

The cornerstone of this reproductive rights framework is that freedom of choice or autonomy is the most important principle in deciding what policies should be adopted regarding reproductive decisionmaking. This view can be described as a libertarian view of reproduction. Under the libertarian view, individual liberty supports individual well-being. So long as individuals are protected from governmental interference in reproductive decisionmaking, well-being remains protected. Under this view, restrictions on editing embryos should be limited as much as possible, so as to promote the principle of autonomy. This focus on autonomy in the libertarian view of reproduction, however, has both strengths and weaknesses.

On the one hand, the libertarian view of reproduction is correct in placing a large emphasis on autonomy. Individuals, not the government, usually know what is best for themselves and their families. This is especially true with respect to deeply personal choices like the decision to have children. Moreover, the history of human reproduction in the

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<sup>187</sup> Dorothy Roberts, *Race and the New Reproduction*, in *THE REPRODUCTIVE RIGHTS READER: LAW, MEDICINE, AND THE CONSTRUCTION OF MOTHERHOOD* 308, 314 (Nancy Ehrenreich ed., 2008).

United States mainly involves infringement on autonomy—from the forced sterilizations in the eugenics movement to the restrictions on access to contraception and abortion that exist today. The right to abortion has slowly become more constrained, and state laws have made access to abortion increasingly limited.<sup>188</sup> Given the trajectory of reproductive rights in the United States, it makes sense to vigorously protect reproductive autonomy.

But on the other hand, the libertarian view of reproduction's singular focus on autonomy leaves little room for discussing the perils of editing embryos. In that respect, the libertarian view overemphasizes the value of individual freedom and neglects to recognize the impact that individual decisions have on future generations. Focusing on a libertarian view of reproductive rights “suggests a thin conception of autonomy and decisional privacy interests, which tends to minimize consideration of other social concerns.”<sup>189</sup> Rather than focusing on isolated actions, the context of editing embryos, unlike other reproductive rights issues, calls for emphasizing how regulation might help promote greater equality and fairness. A libertarian view of procreative autonomy focuses “on our individual goals [which] dissolves community and divides us from each other.”<sup>190</sup> The potentially dangerous societal consequences of editing embryos demonstrate autonomy is not the only value at stake in decisions about this technology. Thus, equating regulation of editing embryos to restrictions on other reproductive activities turns a blind eye to the unique nature of this technology. It also unnecessarily impedes meaningful public policy deliberations about how to handle this technology.

Instead of a libertarian approach to reproduction, which focuses too heavily on autonomy, a helpful, alternative guiding principle of reproductive policy is the reproductive justice framework. Focusing on reproductive justice could facilitate thoughtful public policy discussion about editing embryos, while still emphasizing the concurrent need to protect the right to abortion and contraception. This framework values reproductive autonomy, but also values broader considerations about how public policy regarding reproduction can promote well-being, equality, and diversity. This framework emerged out of concerns raised, especially by women of color, about the “pro-choice” movement's focus on issues that primarily affected white and economically empowered women.<sup>191</sup> For example, Angela Davis argues that the pro-choice

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188. See, e.g., Petition for Writ of Certiorari, *Whole Woman's Health v. Cole M.D.*, No. 15–274, 2015 WL 5169200, at \*32 (2015) (discussing a Texas law restricting access to abortion).

189. See Suter, *supra* note 23, at 951.

190. *Id.* at 952 (quoting CHARLES TAYLOR, *SOURCES OF THE SELF: THE MAKING OF THE MODERN IDENTITY* 206 (1989)).

191. The pro-choice movement has also been criticized for “the politics of exclusion” experienced by women of color, the LGBT community, and the economically disadvantaged. Loretta Ross,

movement failed to address the concerns of working-class women and viewed abortion rights as an answer to “the myriad problems posed by poverty.”<sup>192</sup> Davis points out that early reproductive rights advocates “assumed . . . that poor women, Black and immigrant alike, had a ‘moral obligation to restrict the size of their families.’”<sup>193</sup> These biases crept into the reproductive rights movement and turned what was characterized as a “right” for the privileged into a “duty” for the poor.<sup>194</sup>

In order to address these concerns, a reproductive justice framework refocuses discourse about reproduction on the institutional structures and the social and material conditions under which reproductive choices are made.<sup>195</sup> Reproductive justice goals have been articulated as “creating better lives for women, happier families, and sustainable communities,” and allowing all people to “exercise the rights and access the resources they need to thrive and to decide whether, when, and how to have and parent children with dignity, free from discrimination, coercion, or violence.”<sup>196</sup> A full realization of reproductive justice involves not only negative rights, such as being free from governmental interference, but also certain positive, basic human rights, like equal opportunity. The unregulated use of embryo editing potentially diminishes principles of reproductive justice because these technologies have the potential to exasperate inequalities and discrimination. This framework seeks to organize individuals and communities to actively engage with issues and have critical discussions about reproductive health and decisionmaking, without presuming certain policies to be the “only” correct answer. Reproductive justice focuses on “a view of reproduction as an activity that concerns all society” rather than viewing reproduction as singular, insulated, autonomous choices.<sup>197</sup>

Unlike a libertarian view of reproduction, which seeks to keep all reproductive choices in the hands of individuals, a reproductive justice framework would not necessarily conflict with regulation of technology like the editing of embryos. This framework would neither be strictly for or against regulation. Instead, reproductive justice emphasizes that gene editing is an issue that affects all of society, and therefore warrants

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*Understanding Reproductive Justice: Transforming the Pro-Choice Movement*, 36 OFF OUR BACKS 14, 15 (2007). Reproductive rights scholar Rosalind Petchesky emphasizes in her feminist critique of the “choice” framework that “[the] conjuncture of medical, corporate, and state interests in the ‘management’ of reproduction has defined the choices of all women, but in a way that is crucially different depending on one’s class and race.” Rosalind Pollack Petchesky, *Beyond “A Woman’s Right to Choose,” supra* note 187, at 109.

192. Angela Davis, *Racism, Birth Control, and Reproductive Rights, supra* note 187, at 87.

193. *Id.* at 88.

194. *Id.*

195. *What Is Reproductive Justice?*, IF WHEN HOW, <http://www.ifwhenhow.org/about/what-is-rj/> (last visited Aug. 5, 2016).

196. *Id.*

197. Davis, *supra* note 192, at 110.

democratic deliberation about how to properly regulate this technology. Given the broad society effects of this technology, reproductive justice advocates ought to engage in critical discussions about how editing embryos would impact the goals of reproductive justice. Importantly, the goals of reproductive policy should include not only the promotion of autonomy, but also of dignity, equality, and diversity. Rather than a singular “hands-off” approach to all regulation of reproductive activities, a reproductive justice framework allows advocates to weigh and balance the many implications that regulation would have on social justice goals.

Under a reproductive justice framework, it is not inconsistent to be wary of state interference in reproductive decisionmaking, yet also interested in the public regulation of reproductive technology. For example, law professor Dorothy Roberts has emphasized that disadvantaged groups, such as women of color, are most likely to be harmed by public interference in reproduction issues.<sup>198</sup> But Roberts still contends that “[t]he magnitude of harm that can result from unequal uses of [reproductive] technologies, an inequality rooted partly in racism, justifies government regulation.”<sup>199</sup> Roberts’ perspective emphasizes the need to be aware of the dangers of regulating reproduction, but leaves open the possibility to craft regulatory policy in a way that aims to protect against those dangers. Policies that interfere with decisions about reproduction must be made with the utmost care given the United States’ history of eugenics and restrictions on contraception and abortion. While historical context is important to informing policymaking, a reproductive justice framework also supports public policy about reproduction, which focuses on “eradication of group oppression, and not just a concern for protecting the reproductive choices of the most privileged.”<sup>200</sup> A regulatory system for overseeing the editing of embryos thus supports reproductive justice by promoting public engagement with how embryo editing impacts individuals, their families, their communities, and future generations.

#### B. THE PROBLEM OF POLITICIZING SCIENCE

Another primary concern in regulating embryo editing is the potential to “politicize science.” The phrase politicizing science has been used by genetic reproductive technology expert Marcy Darnovsky to refer to the fear of mixing science and values. For example, when the Obama administration repealed restrictions on stem-cell funding established under President George W. Bush, President Obama promised to make sure that “scientific data is never distorted or concealed to serve a political

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198. Roberts, *supra* note 187, at 318.

199. *Id.* at 316.

200. *Id.* at 318.

agenda—and that we make scientific decisions based off facts, not ideology.”<sup>201</sup> Darnovsky points out that President Obama’s statement assumes that “we want to insulate science from moral values and political commitments.”<sup>202</sup> The real problem with policies like restrictions on stem-cell research, according to Darnovsky, had nothing to do with politicizing science. Instead, progressives rejected restrictions on stem-cell research because the restrictions put corporate and religious interests over the interests of individuals who could reap health benefits from the research. Conservatives’ desire to regulate stem-cell research did not rest on inaccurate scientific beliefs; instead they focused on *values* with which progressives simply disagreed.<sup>203</sup> By framing the stem-cell issue as an issue about keeping politics out of science, rather than deliberating what values should shape scientific policy, progressives “ruled social values out of order in science policy.”<sup>204</sup> Similarly in the context of embryo editing, calls to keep the scientific progress outside the purview of politics rules out any opportunity to discuss how values can help determine how to responsibly edit embryos.

One might also point out that politicizing science may be quite risky for disadvantaged groups. Michele Goodwin, a Professor of Law at the University of California, Irvine, has raised important concerns about whether any system of regulation of reproduction can be applied with equal respect to all women.<sup>205</sup> She argues that historically, mixing regulation and reproductive technology has led to “inconsistent outcomes, unintended consequences, distributional unevenness, decreased utility, and economic inefficiencies.”<sup>206</sup> Goodwin recognizes that scientific and reproductive policy necessarily involves values, but argues that using these values to shape public policy potentially “forces one group’s preferences on another, usually less-powerful group.”<sup>207</sup> Thus, a critical problem with politicizing science is that lobbying groups that drive the legislation are often quite removed from those actually affected by regulations on reproduction. These political actors are often more concerned about the symbolic impact of legislation than practical effects.<sup>208</sup>

The concerns raised by Goodwin, however, should not lead us to take the potential regulation of embryo editing off the table. Instead, while policy surrounding the editing of embryos is debated, it is essential that democratic consideration be broadly inclusive of groups who will

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201. Marcy Darnovsky, *Political Science: Progressives Can’t—and Shouldn’t—Remove Politics and Values from Science*, DEMOCRACY J. 36, 36 (Summer 2009).

202. *Id.* at 37.

203. *Id.*

204. *Id.*

205. Michele Goodwin, *Prosecuting the Womb*, 76 GEO. WASH. L. REV. 1657, 1663 (2008).

206. *Id.*

207. *Id.* at 1671.

208. *See id.* at 1672.

feel the practical effects of laws limiting this technology. Rather than rejecting any connection between science and values, or between science and the state, we ought to consider what the appropriate relationship between these concerns should be. Decisions about editing embryos should be moved from the private realm to the public realm where they can be debated by the broader community.

Darnovsky and others call this quest to involve the community in shaping the values of science policy “biopolitics.”<sup>209</sup> The biopolitics framework contends that considering “social and ethical values in the course of crafting policy is not only appropriate, but necessary.”<sup>210</sup> While consensus over which social and ethical values should shape policy will certainly be hard to come by, “disagreement about social and ethical values, or about how to apply them, is a necessary aspect of democratic political contestation.”<sup>211</sup> Political conversations about editing embryos need to occur because these technologies involve a multitude of questions about social justice, common welfare, and medical and corporate accountability. Editing embryos provides enormous potential for scientific advances and medical improvements, but also enormous potential to deepen the social and economic divides that already exist in our society. Perhaps most importantly, editing embryos raises deep and profound issues about how to have a meaningful life and what it means to be a valuable human being. The answers to these questions shape how individuals see their commitments to others, and how they picture shared humanity communities. For these reasons, it is simply too risky to implement a “hands off” approach to any public engagement with embryo editing. Instead, we ought to engage in democratic deliberation to determine the appropriate relationship between regulation and the editing of embryos.

#### CONCLUSION

The goal of this Note is to point out that the risks of using gene editing technology on embryos for the purpose of creating a genetically modified child call for a deliberate and thorough public policy discussion on how to regulate this technology, and to suggest one way that oversight can take shape. The work does not end here, as Congress and public commentators must continue to deliberate the permissible purposes of editing embryos and the underlying values that regulation of this technology should reflect. In light of the absence of any regulatory mechanism to limit the use of embryo editing in the United States, one

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209. See Darnovsky, *supra* note 201, at 38.

210. *Id.* at 37.

211. *Id.*

option that ought to be seriously considered is implementing a federal regulatory scheme to oversee the editing of embryos.

As our country struggles with the implications of genetic discoveries that expand the potential uses of gene editing, we should not lose sight of the abuses and intolerances that can occur when eugenic ideologies become practice, even if only at the private level. Editing embryos has the potential to alleviate suffering, but also has the potential to intensify inequality and discrimination. We ought to embrace pursuits toward better health and happiness, but be skeptical of pursuits for creating perfect humans. While we struggle to protect women's right to self-determination and control over procreation, we must also keep in mind that we are entering a new era of reproductive technology that does not necessarily parallel the needs of women and families, but rather, follows private investors' market predictions. Public oversight is the best way to encourage the necessary thoughtful deliberation over these issues, because reproduction is an activity that concerns all of society.

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