

## NOTE

### **“IS DOWN ALWAYS OUT?”: THE RIGHT OF ICELANDIC PARENTS TO USE PREIMPLANTATION GENETIC DIAGNOSIS TO SELECT FOR A DISABILITY**

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#### ABSTRACT

*This Note assesses the recent backlash surrounding the near eradication of Down syndrome in Iceland. First, it discusses the various ways in which genetic counseling has played a role in the increased termination of pregnancies with a risk of chromosomal abnormalities. Next, it focuses specifically on preimplantation genetic diagnosis (PGD) as a genetic testing solution to avoid the hardship of pregnancy and subsequent abortion. This Note also considers the use of PGD to intentionally select for a disability, especially with disabilities linked with strong cultures and language such as deafness and achondroplasia. It then compares PGD regulation abroad and PGD regulation in Iceland.*

*This Note argues that current regulation of PGD in Iceland impermissibly infringes on the right to privacy, property, and the right to refuse medical treatment held by prospective parents in Iceland. As a result, prospective parents in Iceland have a right to use PGD to intentionally select for a disability. This Note concludes by recommending Iceland completely deregulate PGD to allow prospective parents full reproductive autonomy.*

#### I. INTRODUCTION

On August 14, 2017, CBS News published an article entitled, ““What Kind of Society Do You Want to Live In?”: Inside the Country Where Down Syndrome is Disappearing.”<sup>1</sup> In the article, Julian Quinones and

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1. Julian Quinones & Arijeta Lajka, “What Kind of Society Do You Want to Live In?”: Inside the Country Where Down Syndrome is Disappearing, CBS NEWS (Aug. 4, 2017),

Arijeta Lajka explore the gradual disappearance of Icelandic babies born with Down syndrome.<sup>2</sup> The article exposes that only one to two babies out of 6,000 per year are born with Down syndrome in Iceland.<sup>3</sup> This shocking statistic correlates to the large influence of prenatal genetic counseling and genetic testing on prospective parents in the country.<sup>4</sup> While the government of Iceland does not require prenatal screening, it does require that all expectant mothers are made aware that genetic testing is available.<sup>5</sup> This requirement alone leads eighty to eighty-five percent of pregnant women in Iceland to take the test.<sup>6</sup>

CBS interviewed expectant mother, Bergthori Einarsdottir, who explained she only took the test after her doctor assured her most women choose to take the test.<sup>7</sup> Ms. Einarsdottir's experience is not unique.<sup>8</sup> As prenatal genetic testing becomes more advanced, it is also becoming more commonplace.<sup>9</sup> Professor Sonia Suter, an expert in genetic counseling, warned against the regularity of prenatal testing, arguing routinization of genetic testing is "problematic" for pregnant women because it reduces choice.<sup>10</sup> Reduction of choice is illustrated in the CBS article. The article states that close to 100 percent of pregnant women who "received a positive test for Down syndrome terminated their pregnancy."<sup>11</sup> This exceeds both the sixty-seven percent termination rate in the United States and the seventy-seven percent termination rate in France.<sup>12</sup> With the significant number of Down syndrome abortions in Iceland revealed, this article received serious attention nationally and internationally.<sup>13</sup>

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<https://www.cbsnews.com/news/down-syndrome-iceland> [<https://perma.cc/6PA9-TXG3>].

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

6. *Id.*

7. *Id.*

8. *See Reference Labs See Average-Risk Patients Fueling Continued Rise in Noninvasive Prenatal Testing*, GENOMEWEB, (Dec. 11, 2017), <https://www.genomeweb.com/clinical-lab-management/reference-labs-see-average-risk-patients-fueling-continued-rise-noninvasive> [<https://perma.cc/NQL2-HRLB>] (explaining the rise of noninvasive prenatal screening has coincided with double-digit growth in prenatal testing each year).

9. *See id.*

10. *See* Sonia M. Suter, *The Genetics Revolution: Conflicts, Challenges, and Conundra: The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 255 (2002).

11. Quinones & Lajka, *supra* note 1.

12. *Id.*

13. *See generally* Alex Kasprak, *Has Iceland Eliminated Down Syndrome Through Abortion*, SNOPEs (Aug. 15, 2017), <https://www.snopes.com/iceland-eliminated-syndrome-abortion/> [<https://perma.cc/V5E9-KWJ8>] (noting the various responses to the CBS News article on the eradication of Down syndrome in Iceland); *see also* Paul Fontaine, *No, Icelanders Are Not Required to Abort Fetuses with Down Syndrome*, REYKJAVÍK GRAPEVINE (Aug. 16, 2017), <https://grapevine.is/news/2017/08/16/no-icelanders-are-not-required-to-abort-fetuses-with-down-syndrome/>

The CBS article sparked a national conversation in Iceland and an international conversation abroad about, as Kári Stefánsson<sup>14</sup> puts it, the “heavy-hand” that genetic testing plays in prenatal decisions.<sup>15</sup> A significant portion of the criticism came from conservative Americans. Sarah Palin, a mother to a nine-year-old boy with Down syndrome, publicly criticized Iceland’s current abortion rate of fetuses with a similar disease.<sup>16</sup> Ted Cruz, a Republican senator from Texas, joined in Palin’s critique, tweeting “Downs children should be cherished not ended.”<sup>17</sup> Numerous news outlets around the globe chimed in, lambasting Iceland for their policy.<sup>18</sup> In response, Icelandic news outlets defended Iceland, arguing the criticism was more anti-abortion than anti-abortion of Downs,<sup>19</sup> and clarifying that Icelandic law does not actually encourage aborting fetuses with disabilities.<sup>20</sup> Regardless of the motivation behind attention to this issue, the probability of babies born with a disability are declining in Iceland due to genetic testing.<sup>21</sup>

The influence of genetic counseling, however, could help parents in Iceland affirmatively choose to carry a baby to term even if it tests positive for a disability. The CBS article focused on prenatal testing of already pregnant women; however, genetic testing can begin before the woman is actually pregnant. Preimplantation genetic diagnosis (PGD) of

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[<https://perma.cc/7CKV-LP77>] (describing the criticism of the information presented in the CBS report); Kate Scanlon, ‘*Let’s be America, not Iceland’: Watch Down Syndrome Advocate’s Powerful Capitol Hill Testimony*, BLAZE (Oct. 27, 2017), <http://www.theblaze.com/news/2017/10/27/lets-be-america-not-iceland-watch-down-syndrome-advocates-powerful-capitol-hill-testimony> [<https://perma.cc/QW2K-DLDW>] (relating the testimony of a man with Down syndrome who referenced the report in Iceland and argued that his was a life worth living).

14. Kári Stefánsson is a geneticist and founder of the largest genetic research facility in Iceland, deCODE genetics. See *Lack of Down Syndrome In Iceland Causes Controversy*, ICELAND REV. (Aug. 17, 2017), <http://icelandreview.com/news/2017/08/17/lack-down-syndrome-iceland-causes-controversy> [<https://perma.cc/24F7-VBVR>] [hereinafter ICELAND REV.].

15. See Quinones & Lajka, *supra* note 1.

16. See ICELAND REV., *supra* note 14.

17. *Id.*

18. See, e.g., Alexandra DeSanctis, *Iceland Eliminates People with Down Syndrome*, NAT’L REV. (Aug. 16, 2017), <http://www.nationalreview.com/article/450509/down-syndrome-iceland-cbs-newss-disturbing-report> [<https://perma.cc/68B9-SARC>]; Dave Maclean, *Iceland Close to Becoming First Country Where No Down’s Syndrome Children are Born*, INDEPENDENT (Aug. 16, 2017), <http://www.independent.co.uk/life-style/health-and-families/iceland-downs-syndrome-no-children-born-first-country-world-screening-a7895996.html> [<https://perma.cc/ZCQ2-TY2P>]; Jeanne Mancini, *People with Down Syndrome are Happy. Why are we Trying to Eliminate Them?*, WASH. POST (Aug. 24, 2017), [https://www.washingtonpost.com/news/posteverything/wp/2017/08/24/people-with-down-syndrome-are-happy-why-are-we-trying-to-eliminate-them/?utm\\_term=.1533bd0900cc](https://www.washingtonpost.com/news/posteverything/wp/2017/08/24/people-with-down-syndrome-are-happy-why-are-we-trying-to-eliminate-them/?utm_term=.1533bd0900cc) [<https://perma.cc/F6BM-YJBV>].

19. See ICELAND REV., *supra* note 14.

20. See Fontaine, *supra* note 13.

21. See Quinones & Lajka, *supra* note 1.

embryos created through in vitro fertilization (IVF) allows mothers to choose the most desirable embryo to implant based on the embryo's genetic makeup.<sup>22</sup> In essence, PGD can eliminate concerns surrounding abortion of fetuses already in the mother's womb because PGD can forewarn a woman prior to implantation of the potential risk of certain disabilities such as deafness, achondroplasia, and Down syndrome.<sup>23</sup>

The ability of prospective parents to "design" a baby raises serious moral and ethical concerns.<sup>24</sup> These concerns range from religious arguments against choosing traits and "playing God"<sup>25</sup> to the potential similarity of PGD to eugenics.<sup>26</sup> PGD receives the most backlash when parents select embryos with a disability, a similar genetic makeup to a sick sibling, or on the basis of sex.<sup>27</sup> There is less controversy when parents use PGD to avoid implanting embryos with a "disability."<sup>28</sup>

This Note argues why prospective parents in Iceland have a legal and constitutional right to use PGD to intentionally select for a disability. Part II discusses the background behind the science of PGD as well as the laws and regulations already in place for PGD use. Part II also discusses the various parts of Icelandic law, such as the Icelandic constitution, which potentially enumerate prospective parents' rights to choose an implanted embryo. Part III argues that current regulation of PGD is unconstitutional and should not extend any further lest it infringe on the rights guaranteed to parents in Iceland. Finally, Part IV concludes and discusses the ramifications if Iceland chooses to allow selection on the basis of a disability.

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22. See Sonia M. Suter, *The "Repugnance" Lens of Gonzalez v. Carhart and Other Theories of Reproductive Rights: Evaluating Advanced Reproductive Technologies*, 76 GEO. WASH. L. REV. 1514, 1515 (2008) [hereinafter *Evaluating Advanced Reproductive Technologies*].

23. *Id.*

24. John A. Robertson, *Extending Preimplantation Genetic Diagnosis: The Ethical Debate: Ethical Issues in New Uses of Preimplantation Genetic Diagnosis*, 18 HUM. REPROD. 465, 465 (2003).

25. LORI B. ANDREWS, *FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS* 57 (2001) ("[A]s more and more prenatal genetic tests become available, parents are increasingly feeling they are put into the position of playing God.").

26. See Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKELEY TECH. L.J. 897, 898 (2007) (discussing "neoeugenics" as the goal of increasing "good birth" on the individual versus state level, and further stating that societal pressures drive potential parents towards selecting against genetic disease).

27. Sarah Aviles, Note, *Do You Hear What I Hear?: The Right of Prospective Parents to Use PGD to Intentionally Implant an Embryo Containing the Gene for Deafness*, 19 WM. & MARY J. WOMEN & L. 137, 139 (2012).

28. See Robertson, *supra* note 24, at 465 ("[M]ost current extensions of PGD are ethically acceptable.").

## II. BACKGROUND

This Section will focus on the science surrounding prenatal testing and preimplantation genetic diagnosis before turning to the Icelandic law. It will describe the primary and more controversial uses of PGD. It will then discuss using PGD to select for, rather than against, a disability, focusing particularly on cultural arguments made by those with deafness and achondroplasia. Next, it will describe the various regulations of PGD internationally, ranging from strict to absence of regulation. Finally, this Section will discuss Icelandic law, focusing first on the various laws and regulations behind reproduction and PGD. It will conclude by outlining the various rights guaranteed to prospective parents in Iceland, drawing from case law, the Icelandic Constitution, and Icelandic legislation.

### A. The Science

As prenatal testing advances, mothers can learn more about their future children earlier in their pregnancies. For example, chorionic villus sampling (CVS) allows a woman to test the fetus only ten weeks into a pregnancy.<sup>29</sup> CVS involves removing the small chorionic villi tissue from the uterus to test for any genetic defects.<sup>30</sup> In addition to CVS, there is an increasing use of nuchal translucency screening (NT).<sup>31</sup> NT is a noninvasive procedure a pregnant woman can undergo during the first trimester of her pregnancy to screen for certain chromosomal abnormalities.<sup>32</sup>

Since the early 1990s, women have been able to test embryos prior to implantation using PGD and IVF.<sup>33</sup> Developed in 1976, IVF allows procreation to occur outside of the womb, as well as noncoitally.<sup>34</sup> IVF is an

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29. See *Chorionic Villus Sampling*, MEDLINEPLUS, <http://www.nlm.nih.gov/medlineplus/ency/article/003406.htm> [<https://perma.cc/2LQJ-7CRL>] (last visited May 21, 2019).

30. Chorionic villus are small projections of tissue in the placenta containing the same genetic structure as the fetus. See *Chorionic Villus Sampling*, STAN. CHILD. HEALTH, <http://www.stanfordchildrens.org/en/topic/default?id=chorionic-villus-sampling-cvs-92-P07769> [<https://perma.cc/F796-PG8Z>] (last visited May 21, 2019).

31. See Helga Gottfreðsdóttir, Jane Sandall & Kristín Björnsdóttir, *This is Just What You Do When You Are Pregnant: A Qualitative Study of Prospective Parents in Iceland Who Accept Nuchal Translucency Screening*, 25 MIDWIFERY 711, 713–14 (2009).

32. Nuchal translucency screening (NT), an early sonography scan, and a blood test comprise the “combined test” most women in Iceland opt to undergo. See KRISTINE FLO HALLE & MARIA FJOSE, *EARLY PRENATAL SCREENING IN ICELAND AND NORWAY* 10 (2016). One study showed 84% of women in Iceland’s capital opted for NT and that between 2004 and 2005, all fetuses diagnosed with Down syndrome were aborted. See Helga Gottfreðsdóttir & Kristín Björnsdóttir, *“Have You Had the Test?” A Discourse Analysis of Media Presentation of Prenatal Screening in Iceland*, 24 SCANDINAVIAN J. CARING SCI. 414, 414 (2010).

33. Jason Franasiak & Richard T. Scott, Jr., *A Brief History of Preimplantation Genetic Diagnosis and Preimplantation Genetic Screening*, IVF WORLDWIDE, <https://ivf-worldwide.com/cogen/oep/pgd-pgs/history-of-pgd-and-pgs.html> [<https://perma.cc/6V8P-W4YJ>] (last visited May 14, 2019).

34. Noncoitally meaning “not involving heterosexual copulation.” See *Noncoital*, MERRIAM

expensive procedure, costing anywhere between a couple thousand to one million U.S. dollars to achieve pregnancy.<sup>35</sup> PGD allows for the genetic testing of embryos created through IVF.<sup>36</sup>

Scientists initially developed PGD to test for chromosomal abnormalities and other risks for disease.<sup>37</sup> But the range of potential PGD uses is broad. A physician can utilize PGD to determine the sex of the future child to avoid sex-linked genetic diseases.<sup>38</sup> Parents may use PGD to screen for heritable late-onset illnesses such as breast cancer or Huntington's.<sup>39</sup> Overall, PGD can "increase the rate of successful embryo implantations, decrease the risk of miscarriages, and eliminate genetic anomalies in the offspring of women of advanced maternal ages."<sup>40</sup> Nevertheless, PGD raises a variety of concerns.

Criticism of PGD is widespread—many fear that an increase in PGD use will lead to a eugenic society where parents design children for the optimal genotype.<sup>41</sup> PGD has controversially been used for sex selection without any risk of sex-linked disease, or used to select an embryo with a tissue match to an existing sick sibling-child.<sup>42</sup> With PGD advancement, the list of "non-medical" PGD usage could expand to include selections based on height, intelligence, or sexual orientation.<sup>43</sup>

In societies where personal liberty and parental freedom of choice are valued, however, some argue prospective parents should be able to screen embryos for either desirable or undesirable traits.<sup>44</sup> The basic argument is that stricter regulation of PGD will lead to more pregnancies that result

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WEBSTER, <https://www.merriam-webster.com/dictionary/noncoital> [<https://perma.cc/5AU5-97B4>] (last visited May 14, 2019); see also Kimberly M. Mutcherson, *Making Mommies: Law, Pre-Implantation Genetic Diagnosis, and the Complications of Pre-Motherhood*, 18 COLUM. J. GENDER & L. 313, 317 (2008) ("Since 1976, the fertility industry has given women the opportunity to have their eggs fertilized ex vivo, or outside of the body, and then implanted in their bodies or that of a chosen surrogate through in-vitro fertilization.").

35. See *The Cost of IVF in Different Countries*, IVF WORLDWIDE, <https://ivf-worldwide.com/education/introduction/ivf-costs-worldwide/the-costs-of-ivf-in-different-countries.html> [<https://perma.cc/P32S-HZWL>] (last visited May 14, 2019).

36. See *Evaluating Advanced Reproductive Technologies*, *supra* note 22.

37. See A.P. Ferraretti et al., *Prognostic Role of Preimplantation Genetic Diagnosis for Aneuploidy in Assisted Reproductive Technology Outcome*, 19 HUM. REPROD. 694, 694 (2004).

38. Mutcherson, *supra* note 35, at 318–19.

39. *Id.*

40. *Id.*

41. See Robertson, *supra* note 24, at 470

42. *Id.*

43. *Id.*

44. See *id.* (arguing PGD for sex selection to achieve familial diversity should be allowed); see also Edgar Dahl, *Ethical Issues in New Uses of Preimplantation Genetic Diagnosis: Should Parents be Allowed to Use Preimplantation Genetic Diagnosis to Choose the Sexual Orientation of Their Children?*, 18 HUM. REPROD. 1368, 1369 (2013) (supporting the position parents should be allowed to use PGD to intentionally select the sexual orientation of their children).

in subsequent abortions if an embryo has an undesirable genetic characteristic.<sup>45</sup> While this argument has merit, it becomes more tenuous when parents use PGD to select for traits relating to a disability.

### B. Selecting for a Disability

It might seem counterintuitive to imagine a parent who would intentionally select for, rather than against, a disability. Indeed, it remains one of the most controversial uses of PGD. One survey of PGD clinics in the U.S. conducted by the Genetics and Public Policy Center at Johns Hopkins University found three percent of prospective parents used PGD to intentionally select for a disability.<sup>46</sup> The parents who chose “defective” genes did not see these conditions as disabilities or as “defective,” but instead as a way for their children to share in the same culture and experiences as their parents.<sup>47</sup> Most commonly, those who select for a disability are selecting for deafness or for achondroplasia, colloquially known as dwarfism.<sup>48</sup>

This desire to share in a culture surrounding a disability is antithetical to typical societal and medical customs. While the medical community tends to view a trait such as deafness as a “condition to be cured,” deaf people perceive deafness and sign language as defining characteristics of a community.<sup>49</sup> Sociologists, linguists, and anthropologists now recognize the deaf population as culturally and linguistically distinct, sharing in common identities and customs.<sup>50</sup> People in the Deaf community not only share a language, but common experiences.<sup>51</sup> Deaf culture is full of customs including widely recognized jokes, stories, and poetry.<sup>52</sup> As such, several studies have found that some deaf parents have a preference for deaf children.<sup>53</sup>

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45. Robertson, *supra* note 24, at 471.

46. See Darshak M. Sanghavi, *Wanting Babies Like Themselves, Some Parents Choose Genetic Defects*, NY TIMES (Dec. 5, 2006), <https://www.nytimes.com/2006/12/05/health/05essa.html> [<https://perma.cc/M436-LZPP>].

47. *Id.*

48. *Id.* Achondroplasia is a genetic disease resulting in developmental disorders, underdeveloped bones, shorter spinal canals, and an enlarged head. See Yao Wang et al., *Advances in Research on and Diagnosis and Treatment of Achondroplasia in China*, 2 INTRACTABLE & RARE DISEASES RES. 45, 45 (2013). The average male adult with achondroplasia is 131 cm tall and the average female adult is 124 cm tall. *Id.*

49. See S.J. Stern et al., *Attitudes of Deaf and Hard of Hearing Subjects Towards Genetic Testing and Prenatal Diagnosis of Hearing Loss*, 39 J. MED. GENETICS 449, 449 (2002).

50. See *id.*

51. See AUDISM UNVEILED (Dawn Sign Press 2008), <https://vimeo.com/ondemand/audismunveiled> [<https://perma.cc/AM3G-ZXR9>].

52. See *id.*

53. See Steven D. Emery et al., *Whose Deaf Genes Are They Anyway?: The Deaf Community's Challenge to Legislation on Embryo Selection*, 10 SIGN LANGUAGE STUD. 155, 156 (2010).

Similarly, parents with achondroplasia want their child to belong to a distinctive community and family unit. One woman with achondroplasia conveyed to the *New York Times* that her desire to have a child with achondroplasia stems from the question “what [would life] be like for her, when her parents are different than she is?”<sup>54</sup> Children of parents with disabilities also share this gravitation towards uniform disability amongst family members. One study found that 36.4% of hearing children with deaf parents at one point or another wanted to be deaf.<sup>55</sup> One such child recalled, “at times I wanted to be deaf. . . I felt so comfortable being around my deaf family and friends. Being with hearing friends, I felt awkward and socially inept.”<sup>56</sup>

Using assistive reproductive technology to intentionally have a child with a disability is not new. In 2002, *The Washington Post* ran an article about a deaf lesbian couple who intentionally selected sperm with a gene for deafness to give birth to a deaf son.<sup>57</sup> These women did not consider it a negative to bring a deaf child into the world; instead, they saw it as a way for their future son to bond with them and their culture.<sup>58</sup> Similarly, a woman named Mary Ellen Little who has achondroplasia, used amniocentesis to find out whether her second daughter would also have the same trait.<sup>59</sup> Additionally, there is at least one reported case of a couple with achondroplasia who corresponded with a researcher to identify the gene for achondroplasia, and assist in genetic screening and abortion of any fetus who did not possess the trait.<sup>60</sup>

But strong opposition exists to allowing PGD selection on the basis of disability.<sup>61</sup> Opponents of this use of PGD insist this selection creates a “harm” to the future child.<sup>62</sup> Opponents claim the harm manifests itself in both the selection and the disability, creating adverse psychological and physical effects.<sup>63</sup> Additionally, most physicians will not allow their

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54. Sanghavi, *supra* note 46.

55. See C. Mand et al., *Genetic Selection for Deafness: The Views of Hearing Children of Deaf Adults*, 35 J. MED. ETHICS 722, 726 (2009).

56. See *id.*

57. Liza Mundy, *A World of Their Own*, WASH. POST (March 31, 2002), [https://www.washingtonpost.com/archive/lifestyle/magazine/2002/03/31/a-world-of-their-own/abba2bbf-af01-4b55-912c-85aa46e98c6b/?utm\\_term=.a09a62dd1c9c](https://www.washingtonpost.com/archive/lifestyle/magazine/2002/03/31/a-world-of-their-own/abba2bbf-af01-4b55-912c-85aa46e98c6b/?utm_term=.a09a62dd1c9c) [<https://perma.cc/S785-VR4B>].

58. See *id.*

59. See Sanghavi, *supra* note 46.

60. See Ronald M. Green, *Prenatal Autonomy and the Obligation Not to Harm One's Child Genetically*, 25 J.L. MED. & ETHICS 5, 6 (1997).

61. See, e.g., Bratislav Stankovic, “It's a Designer Baby!": Opinions on Regulation of Pre-implantation Genetic Diagnosis, 2005 UCLA J.L. & Tech. 3, 2–3 (2005).

62. See *id.* at 37 (discussing the “adverse psychosocial effects” of the “designed” child).

63. See *id.*

patients to use PGD to select for a disability.<sup>64</sup> In their mind, PGD is only about producing “healthy” babies.<sup>65</sup> In addition to physician resistance, some governments’ regulation of PGD make it impossible for parents to select for a disability despite their desire for cultural connectivity.<sup>66</sup>

### C. Regulation of PGD

Regulation of PGD varies widely from country to country, with some countries outright banning all uses of PGD and other countries having close to no regulation at all. Although it extensively regulates PGD, Iceland falls somewhere in between.<sup>67</sup>

#### 1. Extreme Regulation

Few countries have a blanket prohibition on PGD. These countries include Australia and Germany.<sup>68</sup> Regulation of PGD in Australia varies between states, but PGD for non-medical reasons is strictly prohibited everywhere in the country.<sup>69</sup> Additionally, every state only permits PGD to prevent a genetic disease or abnormality.<sup>70</sup> Some states such as Switzerland and Austria ban PGD except in cases of “serious” genetic illness or defect.<sup>71</sup>

Germany passed a law completely outlawing PGD in 2011, except for situations in which there is a predisposition to a serious genetic illness.<sup>72</sup> Even then, however, parents still need to undergo genetic testing and be

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64. Harvey J. Stern, *Preimplantation Genetic Diagnosis: Prenatal Testing for Embryos Finally Achieving its Potential*, 3 J. CLINICAL MED. 280, 284 (2014) (“Most IVF clinicians have indicated that they will not provide PGD to families who seek to select for a disability.”).

65. *Id.*

66. See generally Michelle J. Bayefsky, *Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and its Implications for Reproductive Tourism*, 3 REPROD. BIOMEDICINE & SOC’Y ONLINE 41 (2016), <https://doi.org/10.1016/j.rbms.2017.01.001> [<https://perma.cc/WA47-5K27>].

67. See LÖG UM TÆKNIFRJÓVGUN OG NOTKUN KYNFRUMNA OG FÓSTURVÍSA MANNA TIL STOFNFRUMURANNSÓKNA [ACT ON ARTIFICIAL FERTILISATION AND USE OF HUMAN GAMETES AND EMBRYOS FOR STEM-CELL RESEARCH] (Stjórnartíðindi A-deild 55/1996) (Ice.), translation available at [https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar\\_sidur/Act\\_No\\_55\\_1996\\_on\\_Artificial\\_Fertilisation\\_etc\\_as\\_amended.pdf](https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar_sidur/Act_No_55_1996_on_Artificial_Fertilisation_etc_as_amended.pdf) [<https://perma.cc/LZ79-5RSL>].

68. Tania Simoncelli, *Pre-Implantation Genetic Diagnosis and Selection: From Disease Prevention to Customized Conception*, DIFFERENTAKES, Spring 2003.

69. See *Pre-implantation Genetic Diagnosis*, HEALTH L. CENT., <http://www.healthlawcentral.com/assistedreproduction/pre-implantation-genetic-diagnosis/> [<https://perma.cc/5LM3-GM68>] (last visited May 14, 2019).

70. See *id.*

71. See *id.*

72. See Nishat Hyder, *Germany Allows PGD for Life-Threatening Genetic Defects*, BIONEWS (July 11, 2011), [https://www.bionews.org.uk/page\\_93058](https://www.bionews.org.uk/page_93058) [<https://perma.cc/9XJT-EHBD>].

preapproved by an ethics panel.<sup>73</sup> Regulation of PGD in Austria stems from the “Fortpflanzungsmidizingesetz” or the “Austrian Law on Reproductive Medicine.”<sup>74</sup> In Austria, there is an almost complete prohibition of PGD, with exceptions in rare cases such as potential parental death, miscarriage, or a non-treatable hereditary illness.<sup>75</sup>

## 2. Regulation for Narrow Uses

A significant number of countries in Europe have narrowed the use of PGD to very specific purposes.<sup>76</sup> These countries include France, Italy, Belgium, Greece, the Netherlands, and the United Kingdom.<sup>77</sup> In France, only three centers have permission to use PGD testing on embryos.<sup>78</sup> Within those three centers, a medical professional can only perform PGD when a physician attests to a high risk of a serious hereditary genetic defect, and prospective parents can only use the procedure to search for the purported potential defect.<sup>79</sup> In 2004, Italy passed a law limiting the creation of IVF embryos to three.<sup>80</sup> At the time, this law was among the most restrictive on assisted reproduction.<sup>81</sup> Italy has since relaxed its law, but parents can only use PGD to foster a healthy embryo, or to protect the embryo against a hereditary disease.<sup>82</sup>

The United Kingdom has created an entire agency, called the Human Fertilisation and Embryology Authority (HFEA), to regulate all assistive reproductive technology.<sup>83</sup> In 2008, the U.K. Parliament passed the Human Fertilisation and Embryology Act.<sup>84</sup> Under the Act, the HFEA has the authority to determine how and for what purposes all clinics in the United Kingdom can perform PGD.<sup>85</sup> The Act bans sex selection for

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73. *See id.*

74. *See Preimplantation Genetic Diagnosis: Legal Aspects*, DEUTSCHES REFERENZZENTRUM FÜR ETHIK IN DEN BIOWISSENSCHAFTEN, <http://www.drze.de/in-focus/preimplantation-genetic-diagnosis/legal-aspects> [<https://perma.cc/BQ2U-Q4RL>] (last visited May 14, 2019) [hereinafter *Legal Aspects*].

75. *See id.*

76. *See Aviles, supra* note 27, at 143.

77. *Id.*

78. *See Yves J.R. Menezo et al., Preimplantation Genetic Diagnosis (PGD) in France*, 21 J. ASSISTED REPROD. & GENETICS 7, 8 (2004).

79. *Id.*

80. *Id.*

81. *Id.*

82. *Id.*

83. *Id.*

84. *See Human Fertilisation and Embryology Act 2008*, c. 22 (U.K.).

85. *See Robertson, supra* note 24, at 470.

nonmedical reasons.<sup>86</sup> Most significantly, it bans the selection of embryos at risk of developing a disability.<sup>87</sup> While it is not clear from the Act itself, the explanatory notes indicate that deafness is among the prohibited disabilities.<sup>88</sup>

All three of these countries either explicitly or implicitly ban the selection of an embryo for a disability, denying prospective mothers the right to choose. In Iceland, no such explicit prohibition exists.

### 3. Absence of Regulation

There are very few countries with no regulation of PGD, which include the United States and Mexico.<sup>89</sup> Even the most liberal policies on PGD internationally maintain some provision against sex selection.<sup>90</sup> Notably, the United States and Mexico have no such regulation.<sup>91</sup> The absence of regulation in the United States gives mothers the choice to select an embryo with a “disability.”<sup>92</sup>

Despite the relative rarity of more permissive regulation, some countries are moving in this direction. The chief medical officer of the Department of Health in Ireland, Dr. Tony Holohan, announced that new Irish regulation of PGD will permit sex-selection of an embryo.<sup>93</sup> In addition, the European Court on Human Rights has overturned an Italian ban on PGD screening embryos for cystic fibrosis.<sup>94</sup>

### 4. Icelandic Regulation of PGD and Reproductive Health

The law regulating PGD use in Iceland is less clear than that of other European countries. In general, with respect to laws surrounding reproduction, Iceland is more conservative. Iceland’s abortion law is the “Act

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86. See Human Fertilisation and Embryology Act 2008, c. 22, sch. 2, § 3 (U.K.).

87. See Aviles, *supra* note 27, at 144.

88. *Id.*

89. See Bayefsky, *supra* note 66, at 41; see also *PGD Mexico*, IVF MEXICO (Jan. 8, 2019), <https://www.ivfinmexico.com/pgd/>.

90. See, e.g., Aviles, *supra* note 27, at 140; Human Fertilisation and Embryology Act 2008, c. 22, sch. 2, § 3.

91. See Bayefsky, *supra* note 66, at 43 (quoting the Ethics Committee of American Society for Reproductive Medicine) (“the subsequently revised ASRM Ethics Committee document on sex selection states that ‘there are reasoned differences of the opinion about the permissibility’ of non-medical sex selection, and therefore practitioners ‘are under no ethical obligation to provide or refuse to provide non-medically indicated methods of sex selection.’”).

92. *Id.*

93. See Xavier Symons, *Ireland to Permit PGD*, BIOEDGE (Jan. 20, 2018), <https://www.bioedge.org/bioethics/ireland-to-permit-pgd/12565> [<https://perma.cc/3BWM-8EWG>].

94. See *Costa and Pavan v. Italy*, App. No. 54270/10, Eur. Ct. H.R. ¶ 71 (2012), <http://hudoc.echr.coe.int/eng?i=001-112993> [<https://perma.cc/65YP-884T>].

on Counselling and Education regarding Sex and Childbirth and on Abortion and Sterilisation Procedures.”<sup>95</sup> This law specifically outlines the circumstances in which an abortion is permissible.<sup>96</sup>

Iceland allows abortion for three separate circumstances: when the woman is unable to care for the child; when the child possesses a genetic defect or poses a risk to the mother; or when the woman was raped.<sup>97</sup> Two health care professionals must write a report confirming that one of these circumstances exists prior to the abortion procedure.<sup>98</sup> Furthermore, a physician must advise each woman of the potential health risks of the procedure before the abortion.<sup>99</sup> Additionally, Icelandic law requires the abortion be performed by the end of the 12th week of a pregnancy and specifically prohibits abortions after the 16th week except for extreme circumstances.<sup>100</sup>

Iceland also has substantive laws regarding the use of assistive reproductive technologies in conception and research.<sup>101</sup> First, the law mandates the woman and her partner’s written consent.<sup>102</sup> In addition, a couple must meet certain requirements surrounding their capability of raising the future child.<sup>103</sup> These requirements include the condition of the home the child will live in, and the physical capabilities of the woman to bear and raise a child.<sup>104</sup> This law also addresses embryonic research, allowing research on excess embryos from IVF, but not on embryos created

95. Defining abortion as “a medical procedure undergone by a woman with the objective of terminating a pregnancy before the foetus has become viable.” Art. 8 LÖG UM RÁÐGJÖF OG FRÆDSLUMANNTÖÐIR KYNLÍF OG BARNEIGNIR [ACT ON COUNSELLING AND EDUCATION REGARDING SEX AND CHILDBIRTH AND ON ABORTION AND STERILISATION PROCEDURES] (Stjórnartíðindi A-deild 25/1975) (Ice.), *translation available at* <https://www.government.is/lisalib/getfile.aspx?itemid=2c12d938-f4a1-11e9-9450-005056bc4d74> [https://perma.cc/SQP4-2BYM].

96. *Id.* at art. 9.

97. Social circumstances that would allow for an abortion include when a family is unable to deal with the social ramifications of the pregnancy, when the woman already has a large number of children, when the woman is too young or immature, or when the woman is poor. *See id.*

98. *See id.* at art. 11.

99. *See id.* at art. 12.

100. *See id.*

101. *See* LÖG UM TÆKNIFRJÓVGUN OG NOTKUN KYNFRUMNA OG FÓSTURVÍSA MANNA TIL STOFNFRUMURANNSÓKNA [ACT ON ARTIFICIAL FERTILISATION AND USE OF HUMAN GAMETES AND EMBRYOS FOR STEM-CELL RESEARCH] (Stjórnartíðindi A-deild 55/1996) (Ice.), *translation available at* [https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar\\_sidur/Act\\_No\\_55\\_1996\\_on\\_Artificial\\_Fertilisation\\_etc\\_as\\_amended.pdf](https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar_sidur/Act_No_55_1996_on_Artificial_Fertilisation_etc_as_amended.pdf) [https://perma.cc/D9LK-2HPQ].

102. *See id.* at art. 3 (“Artificial fertilisation may only be carried out if . . . the written and witnessed consent of the woman has been given. If the woman is married [or in cohabitation], the witnessed written consent of the other party must also have been given.”).

103. *Id.*

104. *Id.*

solely for research purposes.<sup>105</sup>

Despite these detailed laws surrounding reproduction, there is currently no Icelandic law regulating PGD use. One can infer regulation of PGD from the Artificial Fertilisation Act and Iceland's membership in the Council of Europe. Article 11 of the Artificial Fertilisation Act allows “research, experiments and procedures on embryos . . . created in order to diagnose hereditary diseases in the embryos themselves.”<sup>106</sup> And in 1997, Iceland ratified the Council of Europe's Convention on Biomedicine and the Additional Protocol Regarding Human Cloning, which establishes guidelines for genetic testing and assisted reproduction.<sup>107</sup> The treaty specifically disallows any medically assisted technique to choose a child's future sex, or genetic testing outside of health and research purposes.<sup>108</sup> Given the typical uses of PGD, some have interpreted Iceland's signature on this treaty as suggesting Iceland restricts PGD for “non-medical” purposes in Iceland, especially as to sex-selection.<sup>109</sup> Nevertheless, Iceland has no explicit regulation of PGD.<sup>110</sup>

#### *D. Rights of Prospective Parents in Iceland*

Despite the ambiguity surrounding regulation of PGD in Iceland, prospective parents maintain significant rights, which extend to reproductive decisions. Three rights in particular are the right to privacy, the right to property, and the right to refuse medical treatment. These three rights, taken as a whole, secure freedom of choice in assisted reproduction.

105. *See id.* at art. 14 (prohibiting the cultivation or production of embryos “solely for research purposes”); *see also* Vilhjálmur Árnason, *Bioethics in Iceland*, 19 CAMBRIDGE Q. HEALTHCARE ETHICS 299, 305 (“The reasoning behind this change is basically the following: Embryos are a human life-form that are deserving of respect and should neither be produced merely as a resource to exploit nor used for trivial purposes.”).

106. Art. 11 LÖG UM TÆKNIFRJÓVGUN OG NOTKUN KYNFRUMNA OG FÓSTURVÍSA MANNA TIL STOFNFRUMURANNSÓKNA [ACT ON ARTIFICIAL FERTILISATION AND USE OF HUMAN GAMETES AND EMBRYOS FOR STEM-CELL RESEARCH] (Stjórnartíðindi A-deild 55/1996) (Ice.), *translation available at* [https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar\\_sidur/Act\\_No\\_55\\_1996\\_on\\_Artificial\\_Fertilisation\\_etc\\_as\\_amended.pdf](https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar_sidur/Act_No_55_1996_on_Artificial_Fertilisation_etc_as_amended.pdf) [<https://perma.cc/L7EX-G8AA>].

107. *See* Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings, *opened for signature* Jan. 12, 1998, C.E.T.S. No. 168 (entered into force Mar. 1, 2001) [hereinafter Protocol on the Prohibition of Cloning Human Beings].

108. *See id.*

109. *See, e.g.,* *Legislation on Biotechnology in the Nordic Countries – An Overview 2017*, NORDFORSK 10–11 (2017) [https://www.nordforsk.org/en/publications/publications\\_container/legislation-on-biotechnology-in-the-nordic-countries-an-overview-2017](https://www.nordforsk.org/en/publications/publications_container/legislation-on-biotechnology-in-the-nordic-countries-an-overview-2017) [<https://perma.cc/LLQ6-UN4C>] (finding PGD restricted against sex-selection in Iceland).

110. *See Legal Aspects, supra* note 74 (“The 1997 Council of Europe's Convention on Human Rights and Biomedicine . . . authorizes diagnostic testing on the human genome under certain conditions. PGD, however, is not explicitly regulated.”).

## 1. Right to Privacy

In American law, the constitutional right to privacy can be interpreted as a right to make reproductive decisions free from governmental interference.<sup>111</sup> This idea comes from the belief that “the decision whether or not to beget or bear a child is at the very heart of [a] cluster of constitutionally protected choices.”<sup>112</sup> Other countries interpret the constitutional right to privacy beyond just “the right to be let alone.” These countries find an affirmative right of the government to protect a woman’s reproductive decisions in the privacy context.<sup>113</sup> Icelandic law has well established the right to privacy in reproductive decisions.

The right to privacy in Iceland is outlined in various international agreements, as well as the Constitution of Iceland. The constitution provides the following:

Everyone shall enjoy freedom from interference with privacy, home, and family life. . . . Notwithstanding the provisions of the first paragraph above, freedom from interference with privacy, home and family life may be otherwise limited by statutory provisions if this is urgently necessary for the protection of the rights of others.<sup>114</sup>

The Supreme Court of Iceland has interpreted this article of the Constitution to include the right to privacy of genetic information, holding in *Guðmundsdóttir v. Iceland* that a woman had a right to withhold genetic information from a public database because the right to privacy extends to personal genetic data.<sup>115</sup>

Article 8 of the European Convention of Human Rights (ECHR) mirrors the idea of privacy in family life. Article 8 provides, “everyone has

111. See *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972) (“If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.”); see also *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1376 (N.D. Ill. 1990).

112. *Carey v. Population Servs. Int’l*, 431 U.S. 678, 685 (1977).

113. See, e.g., Corte Constitucional [C.C.] [Constitutional Court], mayo 10, 2006, Sentencia C-355/06, <http://www.corteconstitucional.gov.co/relatoria/2006/c-355-06.htm> [https://perma.cc/6MDG-J3GV] (in Spanish) (Colom.) (finding women’s reproductive rights needed to be protected by the government by offering adequate reproductive healthcare); see also *Fact Sheet: Nepal Supreme Court’s Landmark Decision Upholding the Right to Abortion*, CTR. FOR REPROD. RTS. (April 26, 2011), <https://reproductiverights.org/document/fact-sheet-nepal-supreme-court-decision-right-to-abortion> [https://perma.cc/7Y2H-UY2K] (describing the Supreme Court of Nepal’s holding that the right to reproductive healthcare includes abortion and is derived from the fundamental right to privacy).

114. STJÓRNARSKRA LÝÐVELDISINS ÍSLANDS [CONSTITUTION] art. 71 (Ice.) [hereinafter ICE. CONST.]

115. *Hæstiréttur Íslands* [Supreme Court of Iceland] 2003-11-27, Case No. 151/2003, *Guðmundsdóttir v. Iceland* (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=cbcba31b-5dfb-4d90-a286-cedc5d095595> [https://perma.cc/325K-RUD8], translation available via *Electronic Privacy Information Center* at [https://epic.org/privacy/genetic/iceland\\_decision.pdf](https://epic.org/privacy/genetic/iceland_decision.pdf) [https://perma.cc/A452-L94K].

the right to respect for his private and family life, his home and his correspondence.”<sup>116</sup> The European Court of Human Rights has made it clear that “private life” includes moral values and physical choice, extending to freedom of choice in one’s sex life.<sup>117</sup> Additionally, the Court has continuously held state interference of privacy rights is prohibited except when necessary for the well-being of society.<sup>118</sup>

With respect to reproductive decisions, the Court has found an affirmative duty to protect privacy interests.<sup>119</sup> The Court is more skeptical when states interfere with choice than when they require consent. For example, the Court found a violation of a woman’s privacy rights when a state refused to perform an abortion at the risk of the mother’s eyesight.<sup>120</sup> But the Court found no privacy violation when a state required a father’s consent for continuing storage of fertilized eggs.<sup>121</sup>

In more than one instance, the ECHR has found a violation of Article 8 when a pregnant mother was denied genetic tests in time to make meaningful reproductive decisions.<sup>122</sup> In another decision, the Court held Article 8 extended to a mother’s right to her embryos created through IVF.<sup>123</sup> The Supreme Court of Iceland has cited the ECHR in upholding the right to privacy in all family relationships, including family relationships by law.<sup>124</sup>

116. European Convention on Human Rights, art. 8 § 1, *opened for signature* Nov. 4, 1950, C.E.T.S. No. 194 [hereinafter Convention]. Article 8 continues:

There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others. *Id.* at § 2.

117. *The Right to Privacy and Family Life*, ICELANDIC HUM. RTS. CTR., <http://www.human-rights.is/en/human-rights-education-project/human-rights-concepts-ideas-and-fora/substantive-human-rights/the-right-to-privacy-and-family-life> [<https://perma.cc/9DDK-JDVH>] (last visited May 14, 2019).

118. *See, e.g.,* Norris v. Ireland, 142 Eur. Ct. H.R. (ser. A) at 18 (1988) (overturning a law which prohibited homosexual acts between consenting adults); *see also* Wallová and Walla v. Czech Republic, App. No. 23848/04, Eur. Ct. H.R. ¶¶ 73, 79 (2006), <http://hudoc.echr.coe.int/eng?i=001-77715> [<https://perma.cc/5M8G-5L6N>] (finding the removal of children solely based on inadequate parental housing incompatible with the Convention).

119. *See* R.R. v. Poland, 2011-III Eur. Ct. H.R. 209 ¶ 184 (finding “positive obligations inherent in effective ‘respect’ for private life”).

120. *See* Tysiąc v. Poland, 2007-I Eur. Ct. H.R. 219 ¶¶ 124, 129, 130.

121. *See* Evans v. United Kingdom, 2007-I Eur. Ct. H.R. 353 ¶ 92.

122. *See* R.R. v. Poland, ¶ 199; *see also* A.K. v. Latvia, App. No. 33011/08, Eur. Ct. H.R. ¶ 64 (2014), <http://hudoc.echr.coe.int/eng?i=001-145005> [<https://perma.cc/LW4A-YV8S>].

123. *See* Parrillo v. Italy, 2015-V Eur. Ct. H.R. 249 ¶ 159 (finding “private life” extended to embryos because the genetic material constitutes a main part of the “mother’s” identity, therefore the mother should be allowed to donate her embryos to scientific research).

124. *See* Hæstiréttur Íslands [Supreme Court of Iceland] 2017-03-30, Case No. 367/2016, A, B & C v. Ice. Nat’l Reg. (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=5470fe9c-fda8-4c08-a1dd-ff014544612f> [<https://perma.cc/4B47->

## 2. Right to Property

In addition to privacy rights, courts have debated whether individuals have property rights in human reproductive material for decades. While there is no clear precedent, some courts have found property rights in material including sperm, gametes, and embryos. In 2009, the U.K. Court of Appeals found appellants owned the frozen sperm they deposited in a hospital, and possessed the right to control use of said sperm.<sup>125</sup> Similarly, some U.S. Courts have held that the progenitors<sup>126</sup> of embryos maintain controlling property rights over them.<sup>127</sup> The property rights of prospective parents in Iceland can be interpreted to extend to reproductive material such as embryos created through IVF.

Like the right to privacy, the Constitution of Iceland and the ECHR govern property rights in Iceland. Article 72 of the Icelandic Constitution provides as follows:

The right of private ownership shall be inviolate. No one may be obliged to surrender his property unless required by public interests. Such a measure shall be provided for by law, and full compensation shall be paid.<sup>128</sup>

The ECHR has similar language in its First Protocol of 1952. In Article 1 of the First Protocol, the ECHR states “every natural or legal person is entitled to the peaceful enjoyment of his possessions.”<sup>129</sup> This distinction focuses not just on ownership, but enjoyment. Additionally, the ECHR gives power to the states to limit property rights when necessary for the public interest.<sup>130</sup>

Even though the provisions of the Constitution and the ECHR do not offer unlimited protection of the right to property, courts have still recognized property rights against public interest.<sup>131</sup> In choosing to deprive

[J727] (holding Article 8 of the ECHR extends privacy protections to family relationships recognized by law).

125. See generally *Yearworth v. North Bristol NHS Trust* [2009] EWCA (Civ) 37 (appeal taken from Eng.) (finding the Human Fertilisation and Embryology Act of 1990 allowed for “absolute negative control” over use and storage of sperm).

126. The ancestors of the embryo, or the creator of the sperm and egg.

127. See *McQueen v. Gadberry*, 507 S.W.3d 127, 148 (Mo. Ct. App. 2016) (holding frozen pre-embryos created through IVF to be special marital property and not “children” or human life); *York v. Jones*, 717 F. Supp. 421, 422 (E.D. Va. 1989) (finding an IVF clinic must recognize the property rights possessed by the progenitors of embryos). These courts tend to define human reproductive material as something more than property, but less than life. See *McQueen*, 507 S.W.3d at 149 (frozen pre-embryos “are unlike traditional forms of property”).

128. See ICE CONST., art. 72.

129. See Convention, *supra* note 116, Protocol No. 1, art. 1.

130. *Id.* (guaranteeing “the right of a State to enforce such laws as it deems necessary to control the use of property in accordance with the general interest”).

131. See, e.g., *Hæstiréttur Íslands* [Supreme Court of Iceland] 2015-05-12, Case No. 541/2015, *Þorvaldsdóttir v. Landsnet* (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=a904dad9-0b00-45b2-9a92->

plaintiffs of property rights, the Supreme Court of Iceland has balanced the proportionality of the public interest versus the right of the plaintiff under the Icelandic Constitution and the ECHR.<sup>132</sup> And the European Court of Human rights has awarded “just compensation” when property is unjustly taken from owners.<sup>133</sup> In all cases, European courts respect property rights, despite limited statutory protection by the states.

### 3. Right to Refuse Medical Treatment & Conscientious Objection

Finally, the right to refuse medical treatment can be extended to reproductive rights. In the United States, “no right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person.”<sup>134</sup> For example, a woman in the United States may be allowed to refuse medical treatment even if such refusal may negatively affect a fetus.<sup>135</sup> European countries have also recognized this right. For example, in *St. George’s Healthcare NHS Trust v. S*, the U.K. Court of Appeal held that a forced caesarean on a pregnant woman violated her right to refuse medical treatment.<sup>136</sup>

Parents are shown less deference, however, to refuse medical treatment when their child is living. When a child is alive, U.S. courts will always balance the interests of the state in protecting the child against the parent’s interest in making the decision.<sup>137</sup> European courts similarly will override the wishes of a parent when a child’s life is at stake.<sup>138</sup>

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4dc827092e4b [https://perma.cc/G8SK-Z7RX] (recognizing the rights of private property owners regarding the laying of electrical cables on their property).

132. *Id.*; see also *Hæstiréttur Íslands* [Supreme Court of Iceland] 2017-06-15, Case No. 193/2017, *Illugason v. Landsnet* (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=5183f2ea-bd38-42e5-a1db-5ee8cb0863e7> [https://perma.cc/BW24-GZHC] (emphasizing the need for proportionality when interfering with property rights in the public interest).

133. See generally *Chassagnou and Others v. France*, 1999-II Eur. Ct. H.R. 21 (awarding compensation to landowners when public hunting was allowed on their property).

134. See *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 269 (1990).

135. See, e.g., *In re Baby Boy Doe*, 632 N.E.2d 326, 330 (Ill. App. Ct. 1994) (holding a competent woman has a right to refuse a cesarean section even if it would be harmful to the fetus). *But see Pemberton v. Tallahassee Mem’l Reg’l Med. Ctr.*, 66 F. Supp. 2d 1247, 1250 (N.D. Fla. 1999) (holding the interest of the State in protecting the unborn child outweighed the mother’s wish not to have a cesarean section).

136. *St. George’s Healthcare NHS Trust v. S* [1998] 3 All ER 673 (Ct. App. (Civ.)) at 692 (Eng.) (“[W]hile pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or not to undergo medical treatment.”).

137. See, e.g., *In re McCauley*, 565 N.E.2d 411, 413 (Mass. 1991) (finding that the State’s interest in a child receiving a blood transfusion outweighed the parents’ religious objection because parents do not have “unlimited” decision-making power over their children).

138. See, e.g., *Re E (A minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386 (forcing medical treatment on a 15 year old even when both the child and his parents refused).

In addition to property and privacy rights, prospective parents in Iceland have the freedom to make individual healthcare decisions. The right to refuse medical treatment is a right based in individual autonomy.<sup>139</sup> It allows an individual to preserve the rights to their own body, and value personal considerations over their health or in some cases their life.<sup>140</sup>

Iceland respects this right to bodily integrity by providing for the right to refuse medical treatment in its “Act on the Rights of Patients.” Article 7 of the Act gives a patient the right to decide to accept or decline medical treatment.<sup>141</sup> The same Article also seeks affirmative consent in writing “whenever possible.”<sup>142</sup> Article 24 of the Act talks about the rights of dying patients, focusing specifically on physical integrity, “[a] terminal patient has the right to die with dignity. If a terminal patient unambiguously indicates he/she declines further life-prolonging treatment, or resuscitation efforts, his/her physician shall respect his/her decision.”<sup>143</sup> Both articles grant the patient the right to refuse or discontinue medical care, despite contrary recommendations by healthcare professionals.

The right to refuse medical treatment is implied under the ECHR.<sup>144</sup> Article 2 of the ECHR protects a right to life.<sup>145</sup> The European Court of Human Rights has construed Article 2 to protect the right to life without creating a “duty to live.”<sup>146</sup> Article 8 protects the right to a private life. In *X v. Austria*, the Court found that “compulsory medical intervention” violated Article 8 privacy.<sup>147</sup> This notion is further solidified in *St. George’s Healthcare N.H.S. Trust v. S*, which held that “[w]hen human life is at stake the pressure to provide an affirmative answer authorising unwanted medical intervention is very powerful. Nevertheless, the autonomy of each individual requires continuing protection.”<sup>148</sup> Finally, Article 12 of the ECHR, focused on the right to found a family, prohibits

139. Elizabeth Wicks, *The Right to Refuse Medical Treatment Under the European Convention on Human Rights*, 9 MED. L. REV. 17, 17 (2001).

140. *Id.*

141. Art. 7 LÖG UM RÉTTINDI SJÚKLINGA [PATIENTS’ RIGHTS ACT] (Stjórnartíðindi A-deild 74/1997) (Ice.), translation available at [https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar\\_sidur/Patients-Rights-Act-No-74-1997.pdf](https://www.government.is/media/velferdarraduneyti-media/media/acrobat-enskar_sidur/Patients-Rights-Act-No-74-1997.pdf) [<https://perma.cc/X7EU-5MAQ>].

142. *Id.*

143. *Id.* at art. 24.

144. See Wicks *supra*, note 139, at 39 (“[W]hen fully applied [the rights and freedoms of the Convention] ensure that each individual has a right to determine how to live their own lives, free from unwarranted interference from the state.”).

145. Convention, *supra* note 116, at art. 2 (“Everyone’s right to life shall be protected by law.”).

146. *Id.* at 21 (describing two cases of the European Court of Human Rights finding that “Article 2 protects a right to life” but cannot “impose a duty to live”).

147. See *X v. Austria*, App. No. 8278/78, 18 Eur. Comm’n H.R. Dec. & Rep. 154, 156 (1980).

148. *St. George’s Healthcare NHS Trust v. S* [1998] 3 All ER 673 (Ct. App. (Civ.)) at 688.

interference with the right so far that the “essence of the right is impaired.”<sup>149</sup>

While the right to refuse medical treatment focuses on patient autonomy, “conscientious objection” (CO) centers on the decisions of healthcare professionals. CO is the refusal of healthcare professionals to provide treatment based on a personal moral objection to a legal medical service such as abortion.<sup>150</sup> The ethics of CO is a heavily debated topic in the field of reproductive healthcare.<sup>151</sup> Currently, Iceland prohibits doctors from exercising CO to providing abortions in public hospitals.<sup>152</sup>

### III. ANALYSIS

Icelandic parents have a constitutional and legal right to use PGD to intentionally select for a disability. Therefore, regulation of PGD in Iceland is unconstitutional and should not extend further lest it infringe on the rights guaranteed to prospective parents in Iceland.

#### A. *Any Regulation of PGD Violates the Right to Privacy Guaranteed to Prospective Parents in Iceland*

Current regulation of PGD in Iceland is in clear violation of the constitutional and legal right to privacy in Iceland. If the treaty from the Convention on Biomedicine and Additional Protocol Regarding Human Cloning regulates PGD in Iceland, PGD is regulated for sex-selection at least, and potentially the selection of other non-medical traits.<sup>153</sup> This regulation might limit parents from selecting for a disability because disability selection could be interpreted as a form of non-medical selection.

The Icelandic Constitution protects privacy in family life and freedom from bodily search.<sup>154</sup> State interference with this right is only allowable when it is “urgently necessary” to protect the rights of others.<sup>155</sup> Regulation of PGD does not meet the standard of urgent necessity. Those in favor of regulation value individual embryos as human life, and believe that the creation and subsequent destruction of undesirable embryos is not only wasteful, but disrespectful.<sup>156</sup>

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149. *Delecalle v. France*, App. No. 37646/13, Eur. Ct. H.R. ¶ 50 (2018), <http://hudoc.echr.coe.int/eng?i=002-12160> [<https://perma.cc/HB7Q-UAPR>].

150. Christian Fiala & Joyce H. Arthur, *There is No Defence for ‘Conscientious Objection’ in Reproductive Health Care*, 216 EUR. J. OBSTETRICS & GYNECOLOGY & REPROD. BIOLOGY 254, 254 (2017).

151. *See, e.g., id.*

152. *Id.* at 256.

153. *See* Protocol on the Prohibition of Cloning Human Beings, *supra* note 107.

154. *See* ICE. CONST., art. 71.

155. *See id.*

156. *See* Árnason, *supra* note 105, at 305.

But this argument fails to consider the potential harm to future fetuses. Parents who are unable to use PGD to select for traits must resort to pregnancy and subsequent abortion of fetuses lacking desired traits. Opponents might point to Iceland's current conservative abortion laws to argue that this is unlikely to happen. Iceland's law, however, allows for some flexibility, such as a woman trying to control the number of children she has, where it might be possible for a woman to abort based on trait preference.<sup>157</sup> Thus, the "urgent necessity" of protecting future human life is negated, while unnecessarily creating the emotional stress of pregnancy and abortion for the woman.

The other problem this argument faces is that one cannot separate the disabled embryo from the disability. The embryo with the trait for deafness will produce a future child with that trait. Therefore, one cannot prevent the disability without preventing that future child's existence. If a healthy embryo is not discarded in place of the disabled embryo, the disabled embryo would be discarded. This forces the argument to be one where a "healthy" existence is valued over existence with a disability.

Additionally, the Icelandic Supreme Court's ruling concerning genetic privacy should extend to genetic decision making.<sup>158</sup> The Icelandic Supreme Court found personal genetic data constitutes information protected by the right to privacy.<sup>159</sup> However, the right to privacy as written in the Constitution extends beyond information to "freedom from interference with . . . family life."<sup>160</sup> Family life includes reproductive matters such as genetic testing and assisted reproduction. Given that the Supreme Court has already found privacy rights with respect to genetic information, it follows the Court can find those same privacy rights with regards to genetic testing.

The right to privacy also encompasses the right of private family life in Article 8 of the ECHR.<sup>161</sup> The European Court of Human Rights has

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157. See art. 9 LÖG UM RÁÐGJÖF OG FRÆDSLUM VARDANDI KYNLÍF OG BARNEIGNIR [ACT ON COUNSELLING AND EDUCATION REGARDING SEX AND CHILDBIRTH AND ON ABORTION AND STERILISATION PROCEDURES] (Stjórnartíðindi A-deild 25/1975) (Ice.), translation available at <https://www.government.is/lisalib/getfile.aspx?itemid=2c12d938-f4a1-11e9-9450-005056bc4d74> [https://perma.cc/7T2E-ZSAR].

158. Hæstiréttur Íslands [Supreme Court of Iceland] 2003-11-27, Case No. 151/2003, Guðmundsdóttir v. Iceland (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=cbcba31b-5dfb-4d90-a286-ceedc5d095595> [https://perma.cc/KNV6-GZKA], translation available via *Electronic Privacy Information Center* at [https://epic.org/privacy/genetic/iceland\\_decision.pdf](https://epic.org/privacy/genetic/iceland_decision.pdf) [https://perma.cc/C8YF-GH8K].

159. *Id.*

160. See ICE. CONST., art. 71.

161. See Convention, *supra* note 116, at art. 8 § 2.

continuously held Article 8 is centered on moral and physical autonomy.<sup>162</sup> If Article 8 extends to a moral freedom of choice, the right of a mother to decide what to do with her embryos should be grounded in her own morality versus a state's imposed moralities. Additionally, the Court found a state's refusal to perform an abortion when there was a risk to the mother's eyesight was a violation of privacy.<sup>163</sup> Like the right to choose sight, the right to choose an embryo is more important than carrying a fetus to term. The essence of the Court's holding is that the State should not interfere with the private right to make choices concerning one's own family.

Article 8 also extends specifically to genetic screening and embryos.<sup>164</sup> Prospective parents in Iceland have a right to "timely" genetic tests.<sup>165</sup> This could potentially extend to PGD, as it is unlikely parents with a disability would choose to abort a child without a disability.<sup>166</sup> Given abortion is unlikely, it may be "timelier" to genetically test embryos created through IVF than fetuses already inside a pregnant woman. Furthermore, because decisions about embryos fall under the Article 8 right to "private life," prospective parents should have a right to decide what to do with embryos created through IVF, free from governmental interference.<sup>167</sup>

Overall, Iceland's various laws mirror both the American "right to be let alone" and the European affirmative right for reproductive privacy.<sup>168</sup> For the former, freedom from government interference can be found in the Icelandic Constitution's own language and the Supreme Court decision about genetic privacy.<sup>169</sup> As to the latter, the European Court of Human Rights has already found an affirmative obligation of the government to respect private reproductive life.<sup>170</sup> Reproductive decisions are central to family life, as well as individual autonomy, and should be given the same consideration as other private family interests. As such, regulation of PGD impermissibly interferes with the familial rights of prospective parents.

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162. See *The Right to Privacy and Family Life*, supra note 117.

163. See *Tysic v. Poland*, 2007-I Eur. Ct. H.R. 219.

164. See *R.R. v. Poland*, 2011-III Eur. Ct. H.R. 209 ¶ 199.

165. See *id.* ¶ 203 ("[T]he nature of issues involved in a woman's decision to terminate a pregnancy is such that the time factor is of critical importance.").

166. See *id.*

167. See *Parrillo v. Italy*, 2015-V Eur. Ct. H.R. 249 ¶¶ 152, 159.

168. See *supra* Section II.D.1.

169. See ICE. CONST. art. 71, cl. 1; see also *Hstirttur slands* [Supreme Court of Iceland] 2003-11-27, Case No. 151/2003, *Gumundsdttir v. Iceland* (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=cbcba31b-5dfb-4d90-a286-cedc5d095595> [<https://perma.cc/6S2H-GUKT>], translation available via *Electronic Privacy Information Center* at [https://epic.org/privacy/genetic/iceland\\_decision.pdf](https://epic.org/privacy/genetic/iceland_decision.pdf) [<https://perma.cc/H9WS-HF7A>].

170. See generally *R.R. v. Poland*.

*B. PGD Regulation Violates the Right to Property Protected by The Icelandic Constitution and the European Convention on Human Rights*

Regulation of PGD in Iceland not only violates the right to privacy but also right to property. If embryos are not considered “human life” as some would argue, they may be considered the personal property of the prospective parents. Courts internationally have already articulated this view, finding prospective parents have use and control property rights of human reproductive material.<sup>171</sup> If Iceland finds a right to exercise control and use of embryos, as in the United States, prospective parents should have complete autonomy to implant an embryo selected for a disability.<sup>172</sup>

However, even if there is no binding precedent finding embryonic property rights, these rights can be inferred from Icelandic legislation. The Act on Counselling and Education regarding Sex and Childbirth and on Abortion and Sterilisation Procedures defines abortion as “a medical procedure undergone by a woman with the objective of terminating a pregnancy before the [fetus] has become viable.”<sup>173</sup> If abortion is performed before viability of the fetus within the first fourteen weeks of gestation, then an embryo that not yet been implanted should not be considered viable at all.

If an embryo is not viable and therefore not considered life, it could be considered the property of the prospective parents.<sup>174</sup> If an embryo is property, Icelandic common law will weigh the property rights of the parents against the public interest,<sup>175</sup> in this case, the interest against “designer babies”<sup>176</sup> or the fear that certain traits might throw off the balance of diversity in society. However, given the exorbitant cost of IVF and PGD, it is unlikely this fear will become a pervasive reality in society.<sup>177</sup>

Another potential public interest might be the welfare of the remaining

171. See *supra* Section II.D.2.

172. See, e.g., *York v. Jones*, 717 F. Supp. 421 (E.D. Va. 1989) (holding parents had right “to exercise dominion and control” over frozen pre-zygote); *McQueen v. Gadberry*, 507 S.W.3d 127 (Mo. Ct. App. 2016) (holding frozen pre-embryos were “marital property” of parents).

173. Art. 8 LÖG UM RÁÐGJÖF OG FRÆÐSLU VARDANDI KYNLÍF OG BARNEIGNIR [ACT ON COUNSELLING AND EDUCATION REGARDING SEX AND CHILDBIRTH AND ON ABORTION AND STERILISATION PROCEDURES] (Stjórnartíðindi A-deild 25/1975) (Ice.), translation available at <https://www.government.is/lisalib/getfile.aspx?itemid=2c12d938-f4a1-11e9-9450-005056bc4d74> [<https://perma.cc/A93J-EFUE>].

174. The embryo could also be seen as having an intermediate status, more than property, but less than life. See *McQueen*, 507 S.W.3d at 148.

175. See *Hæstiréttur Íslands* [Supreme Court of Iceland] 2015-05-12, Case No. 541/2015, *Þorvaldsdóttir v. Landsnet* (Ice.), <https://www.haestirettur.is/default.aspx?pageid=347c3bb1-8926-11e5-80c6-005056bc6a40&id=a904dad9-0b00-45b2-9a92-4dc827092e4b> [<https://perma.cc/JHU8-HN4E>].

176. See *Robertson*, *supra* note 24, at 470.

177. See *id.*

embryos. However, the creation of multiple embryos is unavoidable during the IVF process,<sup>178</sup> and Icelandic law already allows for scientific research of remaining embryos.<sup>179</sup> If researchers can perform genetic tests on embryos, there is no reason the prospective parents—creators of those embryos—should not be able to receive genetic tests if they choose.

Therefore, the prospective parent's interest in having a child of their choosing should outweigh the potential public interests. When the potential public interest is outweighed the Icelandic Supreme Court should uphold the prospective parents' property rights. The language of the Icelandic Constitution provides private ownership "shall be inviolate."<sup>180</sup> Therefore, the private ownership and use of embryos should be respected.

*C. The Right to Choose an Embryo with a Disability is Implied From the Right to Refuse Medical Treatment and the Prohibition on Conscientious Objection*

The rights surrounding a patient's freedom of choice to undergo medical treatment supports intentionally selecting an embryo with a disability. Opponents of disability selection might argue, from the pathological perspective of disabilities, that conditions such as deafness or achondroplasia are medical abnormalities. As a medical abnormality, opponents will opine that selection of these traits creates an unnecessarily more difficult life for a child.<sup>181</sup> However, just as a patient may choose to discontinue life support or choose not to receive treatment,<sup>182</sup> a mother should be allowed to choose a child with a perceived disability.

Prospective parents in Iceland have a right to refuse medical treatment.<sup>183</sup> This right logically extends to intentionally implanting an embryo with a disability. If a prospective parent selects an embryo with a disability over a "healthy" embryo, it could be viewed as refusing the "medical treatment" of discarding embryos with disabilities. Therefore, under the right to refuse medical treatment, prospective parents should be able to intentionally select for deafness or achondroplasia.

Opponents, however, might argue that the right to refuse medical treatment focuses on *individual* autonomy, and imposing a disability on a child extends beyond the individual. These opponents would argue the embryo is closer to an actual child, and therefore the issue is about a pa-

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178. See Jeffrey R. Borkin, *Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis*, 26 J. L. MED. & ETHICS 17, 18 (1998).

179. See Árnason, *supra* note 105, at 305.

180. ICE. CONST., art. 72.

181. See Green, *supra* note 60, at 8.

182. See Wicks, *supra* note 139, at 19.

183. See *supra* Section II.D.3.

rental right to refuse medical treatment of a child, not of one's own person. These opponents would urge Iceland to follow the examples set by the United States and other European nations in weighing parental interests against state interests,<sup>184</sup> and hold that the state interest in protecting the child from a disability outweighs the parent's interest in refusing medical treatment.

But an embryo is not the same thing as a living child, and the Icelandic abortion statute makes it clear "life" in Icelandic law begins at viability.<sup>185</sup> Therefore, the right to refuse medical treatment should be treated in the same way U.S. and European courts have treated pregnant women.<sup>186</sup> Following those courts, Iceland should allow women to refuse medical treatment despite potential "harms" to the fetus.

Even if Iceland were to find that an embryo is equivalent to a living child, Icelandic parents would still have the right to refuse the "medical treatment" of selecting a non-disabled embryo. If Iceland were to truly follow the example set by courts abroad, it would need to balance these interests of the parents against the state.<sup>187</sup> In balancing the interests, most courts are reluctant to go against parents' wishes unless the circumstances constitute life or death.<sup>188</sup> Deafness or achondroplasia are not life or death circumstances, so Icelandic parents should have the right to refuse the "medical treatment" of selecting a different embryo.

In addition to the more explicit rights in the ECHR to refuse medical treatment, there is also the Article 12 right to found a family. This right protects against interference that impairs the "essence" of this right.<sup>189</sup> Stripping parental choice about how one wants to conceive or relate to a child interferes with the essence of this right. The ability to decide how to raise a child is essential to forming a family. When a deaf parent wants a child who can share in their culture, their language, and their community, this goal aligns with how that parent wants to found their family.

Opponents might argue that the right to found a family does not include intentionally selecting for a disability, and going against "god's plan."<sup>190</sup> These same opponents, however, may be less concerned if a mother who undergoes genetic testing chooses to carry a child with Down syndrome

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184. *See id.*

185. *See* arts. 8–10 LÖG UM RÁDGIÖF OG FRÆDSLUM VARDANDI KYNLÍF OG BARNEIGNIR [ACT ON COUNSELLING AND EDUCATION REGARDING SEX AND CHILDBIRTH AND ON ABORTION AND STERILISATION PROCEDURES] (Stjórnartíðindi A-deild 25/1975) (Ice.), *translation available at* <https://www.government.is/lisalib/getfile.aspx?itemid=2c12d938-f4a1-11e9-9450-005056bc4d74> [<https://perma.cc/7GHR-3NAL>].

186. *See supra* Section II.D.3.

187. *See id.*

188. *See id.*

189. Wicks, *supra* note 139, at 36.

190. *See* ANDREWS, *supra* note 25, at 57.

to term, because that fetus was already going to be born with the disability. This argument, therefore, is focused less on the negative implications of the disability itself, conceding it might be okay for a child to live with a disability so long as the parents did not choose it. This argument also fails to consider that the ability to choose to terminate a pregnancy has far greater ramifications than the ability to love and care for a child chosen with “undesirable” traits.

Once it is established that parents have the right to choose to implant an embryo with a disability, doctors should not be allowed to use CO to refuse treatment. The right to implant the embryo of your choice is strongly related to the right to terminate a pregnancy. Both of these rights are derived from reproductive autonomy. Like the prohibition of a doctor refusing an abortion on moral grounds, a doctor should also be prohibited from refusing to implant an embryo with a disability.

*D. Iceland Should Deregulate PGD to Give Prospective Parents Complete Reproductive Autonomy*

Given that PGD regulation in Iceland violates the rights of prospective parents, Iceland should follow Ireland and Italy to lessen restrictions on PGD, ultimately deregulating it completely. Iceland should not follow the extreme examples of Australia, Germany, and Austria, as the regulations in these countries infringe on rights guaranteed to the Icelandic population. Germany infringes on reproductive autonomy by requiring panel approval before PGD is used even for more serious diseases.<sup>191</sup> Austria and Australia go even further than Germany, in most cases completely outlawing PGD without even the potential for panel approval.<sup>192</sup> Since Iceland’s current regulation is already unconstitutional, increased regulation would only further violate Icelandic parental rights.

In addition to infringing on parental rights, adopting an extreme regulation is illogical. A complete ban on PGD prevents parents from receiving genetic information about their future child until implantation. After implantation, the only way to select against an undesired medical or non-medical trait is through abortion. An outright ban on PGD therefore may continue to encourage abortion in Iceland. If the argument against PGD is the protection of the potential life in an embryo, no similar safeguards exist to protect the potential life of a fetus. Therefore, a complete ban may work against the very thing it intends to protect.

Further, Iceland should broaden the legitimate uses of PGD. While opponents may argue against selection for non-medical traits, such as sex or disability, current regulation infringes on parental autonomy and may

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191. See Hyder, *supra* note 72.

192. See *supra* Section II.C.1.

prevent parents from having any children. One could imagine a scenario where the only viable embryo created through IVF contains a disability. While it is unclear from the language of the United Kingdom's HFEA whether the prohibition on selection of a disabled embryo applies in this scenario, it does logically extend from the act.<sup>193</sup> If the only viable embryo is one with a disability and selection of a disabled embryo is prohibited, parents are not only stripped of the freedom to choose a child with desired traits, but potentially the freedom to choose a child at all.

Opponents may argue that if only one viable embryo exists and it has a disability, the government and prospective parents should pursue other avenues beyond deregulation. First, an opponent may argue that parents should not be allowed to select for a disability except in this narrow instance. However, if the argument against disability selection is centered on preventing a potential "harm" to a child, this exception would still create such a "harm."<sup>194</sup> Furthermore, while this narrow exception would mitigate this particular scenario, it would nevertheless still strip parents overall of choice. Specifically, this exception would only allow prospective parents to have a child with a disability when no other viable embryos are available. Therefore, if IVF creates more than one viable embryo, the prospective parents would likely be forced to implant an embryo without a disability.

Opponents may also argue that parents with only one viable "disabled" embryo should instead adopt. However, parents who spend money on IVF and PGD clearly have a strong desire to beget their own children. IVF and PGD are cost-prohibitive to most, sometimes amounting to hundreds of thousands of dollars to achieve pregnancy.<sup>195</sup> In addition to the financial interest, there is an innate interest in wanting a child who shares your genetic makeup. Recommending adoption disregards the importance of both these interests. It disregards the money spent on IVF while simultaneously telling a parent if the embryo they produce lacks "healthy" traits, they are undeserving of having a genetically related child. Finally, adoption would not prevent the embryo from already having existed, so proponents of adoption over implantation are preventing the existence of that future child.

Regardless, Iceland should begin the process of deregulation. Ireland and Italy have already lessened restrictions on PGD, with Ireland controversially allowing sex-selection.<sup>196</sup> However, to respect the rights of all

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193. Aviles, *supra* note 27, at 144.

194. See Stankovic, *supra* note 61, at 32.

195. See *The Cost of IVF in Different Countries*, *supra* note 35.

196. See Symons, *supra* note 93.

prospective parents, Iceland should follow America's example and completely deregulate PGD.<sup>197</sup> Given the controversial nature of using PGD to select for any nonmedical traits as mundane as eye color, it is unlikely any partial regulation would extend to include what could be construed as a "harmful" trait like disability. Only complete deregulation will allow parents with a disability to select for a child who can share in that disability.<sup>198</sup>

However, PGD use to select for nonmedical traits is controversial. The legal selection of embryos with nonmedical traits such as disability might eventually lead to a norm of "designer babies," implicating neoeugenics.<sup>199</sup> Most PGD regulation prohibits the use of PGD to select for physical traits including eye color, height, gender, and of course, disability.<sup>200</sup> Opponents argue that parents should not have the ability to "play god" and use PGD beyond the medical use of avoiding severe genetic disease.<sup>201</sup>

Nevertheless, disabled prospective parents have expressed a desire to raise children with similar traits.<sup>202</sup> "Normal" children of these parents with a disability have expressed this same desire.<sup>203</sup> Regulation of PGD denies these parents the reproductive autonomy to choose a child who can fully share in their culture and lives. And in addition to denying prospective parents autonomy, it also denies them their rights guaranteed to them by Icelandic law. Allowing parents to make decisions about their familial life as early as possible avoids the increased number of abortions that has been much criticized. Therefore, complete deregulation of PGD in Iceland is necessary, and should begin immediately.

#### IV. CONCLUSION

Current regulation of PGD in Iceland should be repealed, and future regulation prohibited. Regulation of PGD impermissibly interferes with the rights to privacy and property, and the right to refuse medical treatment enjoyed by citizens of Iceland. These rights give prospective parents the reproductive autonomy necessary to make decisions concerning embryos created through IVF.

Under Iceland's right to privacy, parents should be allowed to make final decisions concerning family life. Embryonic screening is hardly

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197. See Bayefsky, *supra* note 66, at 41.

198. The only country currently with examples of parents selecting for a disability is the United States where there is no regulation of PGD. See *supra* Section II.B.

199. See Robertson, *supra* note 24, at 470; Suter, *supra* note 26, at 898.

200. See generally *supra* Section II.C.

201. See ANDREWS, *supra* note 25, at 57.

202. See *supra* Section II.B.

203. See *id.*

consistent with the “urgent necessity” required to infringe on privacy rights. Under the right to property, because embryos before implantation are not viable, they should be subject to standard Icelandic property laws. In weighing the proportionality of the rights of the parents versus the public interest, the scale tips to favor the parents because embryonic research still exists regardless of whether nonmedical selection is banned. Finally, under the right to refuse medical treatment parents should be allowed to decide to intentionally select for a disability, and a doctor cannot be allowed to exercise CO to refuse treatment.

The “heavy-hand” of genetic testing in Iceland is demonstrated by the near eradication of Down syndrome.<sup>204</sup> In a 2004–2005 study, every single fetus with a risk for the chromosomal abnormality was aborted.<sup>205</sup> With 84% of women opting to undergo nuchal translucency screening, it is not a surprise that Down syndrome and other disabilities are disappearing from the population.<sup>206</sup> Given these statistics, it is clear that Iceland is encouraging prenatal testing.

However, the routinization of these tests is problematic. Many women opt to undergo the test without truly considering what decisions they will make in light of the results. Additionally, these tests are not always accurate.<sup>207</sup> False positives will lead to some abortions of perfectly healthy fetuses.<sup>208</sup>

The influence of prenatal genetic counseling on abortion poses serious ramifications for the disabled population. The current termination rate may signal to members of disabled communities that their inherent genetic traits are undesirable and unwanted in modern society. In addition, one can imagine a future where a drastic decline in the number of disabled individuals will result in less accommodations or accessibility for the few who remain. For the few individuals whose parents choose to keep them, it is possible they will live their lives in isolation, without a community of individuals with similar traits.

PGD poses a solution to the problem of increased abortions, because mothers can screen embryos prior to implantation and avoid the complicated choice of pregnancy termination. It defies logic to encourage all mothers to undergo prenatal screening leading to an increase in abortion rates, without giving mothers the option to decide what kind of child they want to have before pregnancy. Loosened restrictions could lead to fewer abortions, and potentially more diversity within the population. Parents

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204. See ICELAND REV, *supra* note 14.

205. See Gottfreðsdóttir, *supra* note 31, at 414.

206. See *id.*

207. See, e.g., ANDREWS, *supra* note 25, at 61.

208. See *id.* at 61.

in conventionally disabled populations may choose to opt for a child with their shared disability traits. Iceland may become a country where disability can be selected *for*, and not always against.

But PGD use for nonmedical traits including disability implicates “neoeugenics.”<sup>209</sup> The neoeugenic selection of “positive traits” such as athletic ability or intelligence, raises further moral implications outside the disability debate. And the cost of PGD also presents a potential for wealthy families to gain an advantage in ensuring the superiority of their offspring. Nevertheless, because regulation of PGD infringes on constitutionally protected rights, prospective parents may have the ability to select embryos for more controversial traits than disability.

This constitutional question extends beyond PGD. Scientific advances in reproductive technology may allow parents to genetically alter and modify embryos created through IVF to ensure the “perfect” design. Genetic alteration differs from genetic selection, as prospective parents potentially have the ability to *change* an embryo, for example from hearing to deaf.<sup>210</sup> As the science is relatively new and unavailable on a mass scale, it is unclear whether constitutional protections can or should extend to use of these technologies. If constitutional protections do not allow regulation of these technologies, lawmakers may have to look elsewhere to prevent “designer babies.”

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209. See Suter, *supra* note 26, at 898.

210. See Ekaterina Pesheva, *Single Letter Speaks Volumes: Optimized Gene-Editing System Halts Hearing Loss in Mice with Hereditary Deafness*, HARV. GAZETTE (July 3, 2019), <https://news.harvard.edu/gazette/story/2019/07/gene-editing-tool-prevents-hearing-loss-in-mice-with-hereditary-deafness/> [https://perma.cc/QPU6-UEXG].